Shifting Perspectives: A Strength's Based Approach to Understanding Autistic Development and Support of Autistic Children and Families

By

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Abstract

This thesis is concerned with developing a new intervention to support the well-being of autistic children and their families. It begins with a broad overview of current and historical prominent theories and practices in relation to autism. It concludes that current understanding is inadequate and further insight is needed to inform support of autistic individuals. The thesis moves on to offer two novel theories, the Adapted Phenotype Theory (APT) and Autistic Development Theory (ADT), developed using a complex systems approach. APT, an evolutionary theory, proposes the adaptions lead to an enhanced threat detect and react ability, that is overstimulated in modernity. ADT proposes factors that may influence development of the autistic child with the adapted phenotype and provides potential insight into why there is heterogeneity in the population, the differences between the sexes and life outcomes.

Positive Psychology theory and practice are reviewed in relation to autism. To include the community and involve parents in the planning stage, a proposed programme outline was shared with three focus groups composed of parents of autistic children. Transcripts were analysed using Reflexive Thematic Analysis, and this process generated themes and sub-themes. These themes and Focus Group feedback were used to either adapt existing positive psychology interventions or develop components from scratch.

The thesis then describes how the components were used to form parent workshops, Flourishing Futures. Flourishing Futures is a parent-mediated strengths-based intervention to support the development and well-being of autistic children and their families. Flourishing Futures was evaluated using various parent and child measures and had some outcomes for reducing parent negative experience and increasing affective balance (overall happiness). Parental evaluations on various measures showed some insight into the influence of the workshops on their own autistic children, as did a positive influence on their own (parental) reported social anxiety. Despite some null results, some measures indicated possible positive, although cautious, outcomes for both parents and children.

It is proposed that the findings of Flourishing Futures reflect a shift in parental perceptions, changing the family system, shifting the context of the child and enabling further development. The thesis concludes with potential next steps and further evaluation for Flourishing Futures and empirical testing of the theories. The two theories, Focus Group findings and Flourishing Futures design, operation and outcomes are original contributions to knowledge.

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Finally, Eloise, yes, Granny has now finished her homework!

CHAPTER ONE

INTRODUCTION

Autism is a lifelong neurodevelopmental condition characterised by difficulties in social interaction, communication, and restricted repetitive behaviours and interests (APA, 2013; Rice et al., 2022). There are a wide range of presentations and life outcomes among autistic individuals. Much research has been conducted in this area and continues to evolve, however it has been proposed that the heterogeneity found within the population has impeded explanatory efforts (Waterhouse, 2022). Counter perspectives include the research into how particular character strengths, for example love of learning and honesty, may be very common in autistic people (Kirchner et al., 2016). Indeed, the re-framing of the foundational understanding of autism as a deficit-focused perspective into a greater focus on positive aspects of being autistic provides an opportunity for intervention work even with the paradigm shift it presents (Wright et al., 2024).

The overarching aim of this thesis is to enhance the well-being and life outcomes of autistic children and their families by investigating and developing opportunities for support and intervention. This support aims to enhance life outcomes through understanding autistic development, using a strengths-based focus to achieve developmental goals and reduce stress and anxiety. This focus is integral to Positive Psychology which takes an approach far removed from a deficit-based perspective on autism (Wright et al., 2024). It also acknowledges that if individuals experience the world differently, then the experience of well-being to those individuals (and our conception of it) needs redefining and a greater understanding of what the autistic experience of well-being looks like (Wright et al., 2024).

To achieve this, current evidence is examined and synthesized into two novel explanatory theories. These theories, proposed in Chapter Three, are the Adapted Phenotype Theory (APT) and Autistic Development Theory (ADT). The Adapted Phenotype Theory is an evidence-based evolutionary theory proposing environmental instability leads to core enhancements in threat detection and reaction in predisposed infants. The chapter explores why the enhancements may occur and the functionality of the adaptation in times of adversity. Autistic Development Theory proposes that in modernity, the adaptions may be misaligned with the environment leading to a core disruption in the early infant-caregiver interactions. This may alter the development of social and communication skills. The theory explores multiple other factors that may present a different or altered development and lead to the heterogeneity of presentations and outcomes found within the population.

The thesis moves on to explore what may support autistic children and their families to achieve enhanced development and life outcomes. Family well-being is said to provide the basis for both positive parenting and child well-being. A model that focuses on supporting family and child well-being and strengths, rather than focusing on treating difficulties, has been offered as the Theory of Change model (Newland, 2015). This model proposes that family well-being is a complex construct, but components of parental physical and mental well-being, family self-sufficiency and resilience are essential for family well-being (Newland, 2015). It is proposed that families who are well functioning are more able to adopt developmental parenting behaviours and appropriate affection, responsiveness, teaching, encouragement, engagement with the child, discipline and supportive co-parenting and these are predictive of child well-being. The challenge lies with parental stress, and factors related to this, which have been investigated in both mothers and fathers of autistic children (Di Renzo, Guerriero, Petrillo, & Bianchi di Castelbianco, 2022). The findings showed that, compared to fathers, mothers experienced higher levels of stress related to their parental role which is one factor that directly impacts on family well-being (Di Renzo et al., 2022).

This thesis is focused on considering autism through the lens of a strengths-based approach to both understanding autism as a construct and supporting autistic children and their families alongside enhancing family well-being. It has been proposed that the entire family system is affected by having an autistic child. Relationships with siblings are also reported to diminish over time and family resources may also be impacted (Dijkstra-deNeijs, Boeke, van Berckelaer-Onnes, Swaab & Esther, 2024; Karst & Van Hecke, 2012;). Karst and Van Hecke (2012) propose a model for treatment evaluation for autism that both child outcomes (core autism symptoms, adaptive cognitive and adaptive functioning and treatment specific goals) should be evaluated alongside parent and family outcomes (family functioning, parent-child relationship, parenting efficacy and stress and parent mental health). However, there is merit in approaching interventions with a lens that avoids a deficit-focused perspective (Wright et al., 2024).

The mental health problems of autistic children and adults are widely reported. Autistica, a UK-based autism research charity, reports that seven out of ten autistic children have a mental health condition, and four in ten have more than one, with anxiety being the most commonly co-occurring condition (Adams & Young, 2021; Harper, Smith, Simonoff, et al., 2019; Neilson & Bond, 2023). Adding to the challenges faced by autistic children is the reported *'routine denial'* of access to Child and Adolescent Mental Health Services (CAMHS) as described in research findings (Harper, Smith, Simonoff, et al., 2019, p.1). The report also states that some mental health problems are considered 'untreatable' as mental health professionals often confuse mental health symptomology with autistic symptomology or

CAMHS practitioners feel inadequately equipped to support them (Harper, Smith, Simonoff, et al., 2019). A report on suicide prevention states that up to 11% of people who die by suicide in the UK may be autistic, with suicide being the leading cause of early death within the autistic community (Harper, Smith, Cassidy, et al., 2019). These issues may suggest the current understanding of autism and support of autistic people (both separate to a non-deficit perspective, e.g. a positive psychological strengths-based approach) could be inadequate which may be an influencing factor in the reported outcomes.

Historical theories and practices have in some cases created a division between researchers and some autistic advocates who question the aims of the research community (Milton, 2012, 2014b) and seek to be involved in research alongside other stakeholders (Pukki et al., 2022). Division also exists within the autistic community itself, with some advocates seeking support and acceptance, while others call for a 'cure'. For example, a group of autistic academics shared concerns regarding the launch of ‘Spectrum 10k’, the UK’s largest genetic autism research project. The key concern being expressed by the autistic community is that the genetic database will be used for eugenic purposes in the future. In an article, they reported that social media has seen fierce opposition to the research from autistic people, yet many feel that their fears have been dismissed (Chapman et al., 2021). These few examples of the current debates and divisions lead to the consideration that autism may be described as a ‘wicked’ problem. ‘Wicked’ problems are said to involve emotion, secrecy, divisions, competition, distrust and resistance, and these are thought to hinder learning and trust (Noordegraaf, Douglas, Geuijen, Van, & Steen, 2019). Wicked problems are said to be:

"by nature, adaptive, participatory, and transdisciplinary (APT for short). By examining a wicked problem as a whole through a panoramic social lens rather than a scientific microscope, and working with it through an open and heuristic process of collective learning, exploration, and experimentation, the APT approach promises to be efficacious in fostering collaborative behaviour, reducing conflicts, building trust among all stakeholders and communities involved, and ultimately producing better and more satisfying results" (Head & Xiang, 2016, page 4).

It is suggested in this thesis that researchers would be in a better position to address ‘wicked problems’ by employing an adaptive, participatory, and transdisciplinary approach (APT). An APT approach was applied to the research of this thesis, which was also supported by the insights gained through being a parent to an autistic person and a practitioner in the field of autism. As a parent, I am aware that the current understanding of autism does not fully reflect my son’s lived experience. Many challenges faced in the past

are not currently associated with autism and this has also been reflected in my work with families. As a practitioner, much of my work has focused on the experiences and challenges that were not considered part of the autism spectrum. In my professional life, I have found children were either receiving additional diagnoses to account for their challenges or no appropriate support for them. These personal and professional perspectives were drawn upon to focus and frame questions for this thesis and in part helped to guide the research process.

Using lived experience from working as a parent and a practitioner also helped to explore concepts of this research and gain further insights that supported the development of the theories reported in this thesis - The Adapted Phenotype Theory and Autistic Development Theory. Of paramount importance throughout the research and writing-up process has been to bring compassion to the forefront and ensure autism is theorised and supported with the respect and dignity that is deserved.

Aims

The initial overall aim of the research was to develop and evaluate an intervention programme that uses Positive Psychology to enhance the well-being of autistic children and their families.

The following section briefly describes the framework used within this thesis for the development of complex interventions. The evaluation of the theoretical approaches to understanding autism are, therefore, used to inform the development of a later invention.

Framework for Developing Complex Interventions

The UK Medical Research Council and the National Institute for Health Research have jointly provided a new framework to guide the development and evaluation of complex interventions (Skivington et al., 2021). The guidance highlights that previous intervention models focused solely on effectiveness, potentially limiting cost-effective and scalable solutions.

The guidance considers a complex intervention to be one that may involve several components, target a range of behaviours, require expertise from those delivering the intervention, or have flexibility in the intervention or its components (Skivington et al., 2021). An intervention that is informed by a variety of sources, targeting a range of behaviours and seeking to support a wide age range of children, as is the case in this thesis could be considered ‘complex’.

The framework for developing complex interventions is divided into the phases of: feasibility, development of the intervention, evaluation and implementation. Each phase shares core elements of context, programme theory, stakeholders, key uncertainties, intervention refinement and economic considerations.

Context refers to the various external factors that influence intervention outcomes, such as physical, social, and economic environments. For example, an intervention effective in one setting may not yield the same results in another. Interventions may also serve to modify the context, such as creating responses from other agents or changing norms. Context is, from this perspective, multi-dimensional and dynamic, and the effects of interventions may change over time.

According to the framework, programme theory should be created at the start of the development of the programme, including stakeholders, and be based on evidence and theory from relevant fields. Programme theory should describe how the intervention is expected to work, the key elements, how the elements interact and the mechanisms of the intervention. Programme theory should identify both how context influences intervention

mechanisms and how interventions, in turn, modify the context. The programme theory should be refined at the different phases during the research.

Stakeholders may include the target population, public members, intervention developers, and professionals impacted by the intervention. In the design and delivery of the research, a pragmatic approach is necessary as there are many uncertainties involved. Therefore, a flexible and emergent approach is needed to explore them. Key uncertainties should be identified, and questions may be answered at each phase. This framework recognises the translation of more traditional research evidence into different settings in practice can be challenging. The framework states:

> *For intervention research in healthcare and public health settings to take on more challenging evaluation questions, greater priority should be given to mixed methods, theory-based, or systems evaluation that is sensitive to complexity and that emphasises implementation, context, and system fit. This approach could help improve understanding and identify important implications for decision-makers, albeit with caveats, assumptions, and limitations,* (Skivington et al., 2021. p.1).

Each phase of the complex intervention research should lead to refinement of the intervention based on findings and programme theory development. The refinements undertaken in each phase should lead to improvements in the feasibility and acceptability of the interventions.

Economic considerations are another core element of developing complex interventions, with economic evaluation being a core component of each phase. This may be a broad cost-benefit analysis that aims to capture a wide range of health and non-health costs and benefits across different sectors, rather than more specific approaches such as cost-effectiveness.

The phases of this are developing or identifying a complex intervention, feasibility, evaluation, and implementation. There are two distinct paths to the development of a complex intervention. Intervention identification is adapting an existing intervention to a new context. The second is intervention development. Intervention development is identifying the underlying theoretical basis for the intervention, developing programme theory, uncertainties and how to evaluate the programme. This thesis aligns with the intervention development phase, focusing on the theoretical foundation and evaluation strategies.

A feasibility study should be designed to assess progression criteria related to the evaluation design or the intervention. A feasibility study for the intervention could be focused on content, implementation issues and factors that may affect the cost-effectiveness,

effectiveness and acceptability of the intervention. The feasibility study should also consider if the expected benefits outweigh the cost of the intervention.

The new framework goes beyond finding if an intervention works to asking broader questions such as identifying what other impact it has, theorising on how it works, how it interacts with the context, the way it supports systems change and how the evidence can be used to support decision making in the real world. Outcome measures should not make a distinction between primary and secondary outcomes, especially when the programme theory identifies potential impacts across a range of domains. Subgroup analyses should be undertaken and even if underpowered these should be reported. Outcomes may be changes to a system or a person.

In summary, complex interventions should involve various phases and consider how the intervention interacts with its context, the underlying theory that drives the intervention, the inclusion of stakeholders, identifying uncertainties, and the resource outcomes, and be flexible and enable refinement. As the work pertained to in this thesis fits into the new framework, the thesis will apply the above framework where applicable.

The following section provides an overview of the remaining chapters in this thesis and an indication of the methods used in this research.

Overview of Chapters

Chapter Two seeks to explore the current landscape of autism. In doing so, the prevalence of autism and the human and economic costs of autism are discussed, as are the most prominent current and historical theories, approaches and interventions. The theories are discussed under the headings of autism as a diagnostic concept, as cognitive deficits and perceptual differences. As this chapter seeks to provide a picture of the current landscape, common myths and misconceptions are also considered alongside how these may further impact the development and well-being of autistic children and external opportunities.

The chapter also provides an overview of the mental health problems that most commonly occur in the autistic population and the reported challenges experienced when seeking mental health support.

The combination of myths, misconceptions, widespread mental health problems in the autistic population and challenges to obtain mental health support all prompt the researcher to believe new thinking and approaches are needed to move forward. The chapter concludes that the case for an intervention that aims to enhance autistic children's mental health is justified and likely to be beneficial to the community.

Chapter Three focuses on the potential causes of autism and examines possible evolutionary origins and influences. This is explored from the developmental evolutionary psychology perspective and proposes that autism may be a form of ‘adaptation’ to adverse environmental conditions, rather than a pathological process. The concept of adaptation opens the possibility that this may be considered a strength developed to cope with the expected environment post-birth.

In essence, the chapter proposes that the core adaptions to adverse maternal conditions are an enhanced superior colliculus (a brain region that processes simple sensory stimuli and peripheral vision) (Jure, 2019) and hypothalamic-pituitary-adrenal (HPA) axis (the brain’s stress response system). These adaptations are proposed to enable the infant to have an enhanced ability to detect and react to threats. The adaptiveness of the proposed core differences are considered concerning both childhood and adult life. The chapter recognises that the advantages of the autistic phenotype are potentially at odds with modernity and can become maladaptive in environments with too much sensory stimuli.

Chapter Three includes a timewise divergence test, which is an estimate of the date that the last known common ancestor of two species diverged. The species that share the adaptation of an enhanced Superior Colliculus (*Hemichromis bimaculatus* - Jewel fish) and the species that share the enhanced HPA axis (*Danio rerio* - Zebra fish), were tested against Homo sapiens. The timewise divergence test gives an approximate date of the last known common ancestor of both species. The chapter concludes that the proposed evolutionary adaptations may be very ancient and as they may be shared with other species, are likely to be highly beneficial for survival at times of environmental instability.

In biological sciences, ‘proximate’ and ‘ultimate’ explanations are sought, and it is deemed to be appropriate for science to provide both. Ultimate explanations seek to explain why an organism has a trait (Otsuka, 2015), while proximate explanations explain how it works. The Adapted Phenotype Theory of autism proposed in this chapter is an ‘ultimate’ scientific explanation and is an original contribution to knowledge.

The chapter builds on the previous theory by taking a complex systems approach to generate Autistic Development Theory (ADT), a proximate scientific explanation. The complex systems approach acknowledges that there may be a single root cause, but factors at multiple levels may influence health and disease and these may inter-relate and include feedback and changes over time (Galea, Riddle, & Kaplan, 2010; Kühne et al, 2022). The complex systems approach helps to identify factors that could influence autistic children's development and the chapter provides a visual model of these inter-related factors.

ADT proposes that attention and social communication development are disrupted through enhancements in the superior colliculus (SC) and the HPA axis affecting early interactions with caregivers. These enhancements are proposed to affect the dyadic interactions that infants and carers have, which are the building blocks of attention, social interaction, and communication. These infants may be hyper-plastic (Markram & Markram, 2010) in their learning ability, and given appropriate environments, learning and development are possible throughout their lifetime. The proposed more developed SC, which is involved with attention and drives social motivation (Jure, 2019), may mean that when conditions are tolerable, the child can learn the skills that may have been delayed.

The chapter moves on to describe another nine factors that may further influence development. These are:

1. Anxiety leading to simple and complex avoidant behaviours
2. Right Developmental Behaviour, Wrong Time
3. Chronic Stress
4. Parental Influences, e.g. parental stress
5. Mental Health Diagnoses
6. External Influencers, e.g. expectations from teachers
7. Affectedness is Context Dependent
8. Sex Differences Influence Behaviour
9. Special Interests Are Motivating and a Strength

The chapter concludes with the possibility that understanding autism from the perspective of ADT may better inform parents and practitioners and enable enhanced outcomes for children. In contrast to the previous theory APT, ADT is a proximate explanation (Otsuka, 2015), of the developmental and physiological phenomena that may occur over a lifetime. Autistic Development Theory is an original contribution to knowledge.

Chapter Four shifts the focus to examine how ideas drawn from the area of positive psychology, with its focus on strengths and well-being, may have the potential to help autistic children's and their families' well-being. The ethos of the 'Spaces of Well-being' theory (Atkinson, 2013), which proposes that well-being is situational and context-driven, is discussed with a view to this being an underlying ethos of the proposed programme. Key theories and approaches, such as the 'broaden and build' theory of positive emotions (Fredrickson, 2011) and the 'PERMA' model of well-being (Seligman, 2018) are discussed to help parents understand what components can be built into life to enhance family well-being

and build resilience. The chapter concludes that positive psychology has much to offer autistic children and their families.

Chapter Five, moving into research design, reports on focus groups undertaken with parents of autistic children to ensure that the views of families for whom the programme is intended, inform its development. There has been a call from the autism community for participatory research involving a partnership between researchers and people who are affected by the topic of investigation (Chown et al., 2017). As the aim is to develop a parent-led intervention for autistic children's well-being, sharing ideas and decision-making with parents is essential if the work is to be considered participatory. Three focus groups were conducted, with each one focused on families and parents of autistic children in different age ranges: primary-level education, secondary-level education, and parents of young adults. Parents were asked to comment on a broad proposed outline of the programme and share their ideas for inclusion and the needs they and their children had. The qualitative method of Reflexive Thematic Analysis (Braun & Clarke, 2006; 2021) was applied to identify themes taken from the transcripts of the focus group discussions.

The analysis found parents involved in the focus groups to be supportive of a strengths-based intervention and thought that it should be available at the point of diagnosis. The challenges faced and concerns over children of families in the focus groups differed across the age groups. Participants described what may be considered as them experiencing a 'journey'. Parents of the younger children wanted to know more about autism and sought information, guidance, and a vision for the future. Some parents of secondary-aged children appeared over-whelmed, stressed and felt let down by a lack of understanding and appropriate support for themselves and their children. In contrast, parents of young adults appeared accepting of their children's continued development and their role within it. These parents also displayed different coping strategies, such as using humour during discussions. The themes and stories that emerged from the focus groups are an original contribution to knowledge.

Chapter Six describes the creation or adaption of components for development and well-being. The chapter explores the needs to be addressed as identified through the literature review, the current landscape, Autistic Development Theory, and the themes from the focus groups. As per the framework for developing complex interventions (Skivington et al., 2021a) the theory of why each component could be helpful is discussed. The components are an original contribution to knowledge. The separate components are used to develop an intervention which is the focus of Chapter Eight.

Chapter Seven describes the development of a parent-mediated intervention, 'Flourishing Futures'. Flourishing Futures are parent workshops that enable parents to learn ADT, stress reduction strategies and strength-based development and planning.

As an initial trial of the programme, 43 parents of autistic children were recruited, of whom 24 were allocated to an 'evaluation group' (who undertook the programme) and 19 to a 'wait-list control' group who subsequently undertook the programme. Measures of parental well-being and child anxiety and autism symptoms were used pre- and post-intervention. It was found that parent participation in the programme improved parent 'affective balance' which is an indicator that parents may be happier, compared to no change in the 'wait-list control' group. Children in the 'evaluation' group were reported as showing decreased autism symptoms and social anxiety, that were not found in the 'wait-list control' group.

The use and results gained from statistics in this context were challenging. Despite huge effort being invested into participant recruitment, the numbers eventually involved placed pressure on achieving a broader statistical significance.

The chapter reflects on the challenges of participant recruitment in autism research and how this has changed during the time of this thesis. The chapter reflects on the outcomes of statistical measures and how the results may still be positively evaluated in the context of views expressed by the UK Medical Research Council and the National Institute for Health Research seeking cost-effective and scalable interventions. The chapter concludes that the 'Flourishing Futures' programme may be a cost-effective intervention that warrants further development and evaluation and is an original contribution to knowledge.

In the final chapter, Chapter Eight, an overview of the work presented, and the contribution to knowledge is provided. The implications of APT and ADT are discussed in relation to education, adult support, autism as a diagnosis and medications being used to manage behaviour. Suggestions for further research are offered, which include testing of the theories and further evaluation of 'Flourishing Futures'.

The chapter also proposes that the presentations of autism, highly sensitive people and giftedness may share commonalities. These seemingly unrelated conditions may share the same core difference as autism, leading to high sensitivity and anxiety. It is also speculated that enhancements of the superior colliculus and/or the HPA axis may be the underlying cause of dyslexia and ADHD and these proposals may also warrant further investigation. The chapter concludes that, whilst the project's initial overall aim of developing a strengths-based programme to support the well-being of autistic children and their families was met, the research also took significant steps in contributing to theoretical work around why autism occurs, as well as the factors that may influence the development

of autistic people. The aims of the research have been achieved and leave potential for further research to be undertaken to further develop, and test, the theoretical contributions and to replicate, and extend the findings of ‘Flourishing Futures’.

The following chapter reviews current research and practice and the most prominent mental health co-occurring diagnoses.

CHAPTER TWO

AUTISM: CURRENT UNDERSTANDING AND HISTORICAL INFLUENCES ON RESEARCH AND PRACTICE

Introduction

This chapter aims to provide insight into the current understanding of autism, examining both its present conceptualisation and the most influential historical theories that have shaped practice and perception. Research on autism has been extensive, rigorously developed, and empirically tested and deepening our understanding of cognitive functioning.

While some theories have evolved, outdated practices and misconceptions influenced by earlier models persist in public discourse. This chapter highlights the limitations of current theories in fully capturing the complexity of autism and explores their implications for supporting autistic individuals in reaching their full potential.

This chapter will examine the existing literature on autism, covering:

- The prevalence and economic impact of autism
- The historical development of autism as a diagnosable condition, including theories of causation and intervention approaches
- The co-occurrence of mental health conditions in autistic individuals

The review will begin by providing a brief overview of the diagnostic criteria for autism.

Diagnostic Criteria

Autism is described as a neuro-developmental condition with a diagnosis based on difficulty or differences in social interaction, communication, thought flexibility, and repetitive behaviour (Aylott, 2000).

The DSM-5 criteria provide a single diagnosis of Autism Spectrum Disorder, which replaced previous diagnoses of Aspergers Syndrome, Autistic Disorder, Pervasive Development Disorder, and Childhood Disintegrative Disorder (Volkmar & McPartland, 2014). There are two domains of the diagnostic criteria; these are:

- Social communication
- Fixated interests/repetitive behaviour or activity

The DSM-5 provides the following diagnostic criteria for autism spectrum disorder:

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history:

1. Deficits in social-emotional reciprocity;

2. Deficits in nonverbal communicative behaviours used for social interaction;

3. Deficits in developing, maintaining and understanding relationships.

B. Restricted, repetitive patterns of behaviour, interests or activities as manifested by at least two of the following, currently or by history:

1. Stereotyped or repetitive motor movements, use of objects, or speech;

2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour;

3. Highly restricted, fixated interests that are abnormal in intensity or focus;

4. Hyper- or hypo-reactivity to sensory input or unusual interest in the environment's sensory aspects.

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay, (Vivanti & Pagetti-Vivanti, 2017, p. 1).

There are three levels of severity in the diagnosis, determined by the level of support an individual requires. This classification is assigned at the point of diagnosis; however, its validity has been subject to scrutiny. A study involving 248 children diagnosed with autism evaluated their severity levels and found that higher severity was associated with younger ages (Mazurek, Lu, Macklin, & Handen, 2019). This raises concerns that labelling younger children with high severity may inadvertently lower expectations and limit their exposure to developmental opportunities. Such limitations could, in turn, constrain developmental outcomes.

Prevalence of Autism

A UK study reported a prevalence of 1% of adults within the community in 2012 (Brugha et al., 2012). Secondary data analysis of the Millennium Cohort Study, a longitudinal study of 18,522 children born in the UK in the year 2000 (Dillenburger, Jordan, McKerr, & Keenan, 2015), reported the following prevalence rates at different ages:

- Five years old: 1 in 111 children
- Seven years old: 1 in 59 children
- Eleven years old: 1 in 29 children

Further to this, a longitudinal study of the UK's total school population found that by 2018/19 the prevalence rate of autistic pupils was 3.20% in Northern Ireland, 2.25% in England, 2.51% in Scotland and 1.92% in Wales, giving a UK average of 2.47%. A UK prevalence study used the Spring School Census 2017, which holds information on all 2 – 21 year olds in state education, reported a prevalence of 1.76% (Roman-Urrestarazu et al., 2021). Given that these percentages are for pupils in schools, and high rates of special needs and autistic children being excluded from school (Secretary of State for Education, 2019), the actual prevalence rates may be higher.

The ratio of diagnosis between males and females is approximately three males to one female (Loomes, Hull, & Mandy, 2017), indicating a gender bias in either autism occurrence or diagnosis. A recent study found that between 1998 and 2018, there had been a 787% rise in autism diagnosis, with greater increases for females than males and the greatest rises in adult diagnosis (Russell et al., 2022).

Given the prevalence of autism, it is important to consider the financial cost to the economy and the human costs to individuals.

The Economic and Human Cost of Autism

A European study found that the costs of health services and societal costs were €2834 over two months, and this rises with age (Bieleninik & Gold, 2021). The economic cost of autism to the UK is estimated to be £32 billion per year, with £3.1 billion of aggregated costs for children and £29 billion for adults. Aggregated costs are to families, special education, medical provision, social care provision, employment support, benefits, accommodation and underemployment of autistic adults. The costings used to inform the study were from 2010-2011 (Buescher, Cidav, Knapp, & Mandell, 2014), and the estimated £32 billion in 2014,

rises to £47,047[1] billion for 2014 when inflation is taken into account ("Inflation calculator | Bank of England," n.d.).

These costs are based on an adult prevalence of 1%, therefore, using the latest prevalence figures, there is the potential that adult autism costs to the economy may rise exponentially if the current situation does not change.

Dillenburger et al. (2015) reported risks to autistic children of poor mental and physical health, poverty and social exclusion, both pre-and post-diagnosis. They suggest that the detrimental impact on children would increase over time, and children's rights under the United Nations Convention on the Rights of the Child, and the UN Convention on the Rights of Persons with Disabilities, are not being met.

Further to this, a literature review focusing on adult outcomes reported that adults had little social integration, poor job prospects, and high mental health rates (Howlin & Magiati, 2017). It has also been reported that autistic people may experience a shorter lifespan and higher rates of suicide than non-autistics (Hirvikoski et al., 2016). Autistic people have also been reported to have a seven times increased risk of suicidal behaviour in comparison to the general population (Hedley, Hayward, Clarke, & Uljarevic, 2022). Negatives outcomes such as these are countered with a greater understanding of autism, both theories and perspectives (Wright et al., 2024).

The following sections of this chapter discuss historical and current autism theories and practices.

Characteristics of Good Autism Theory

Flecher-Watson and Happe (2019) propose that a good autism theory should give a casual account that helps to understand and support autistic individuals. They propose six ideas on what to look for in a good autism theory are:

1. Concrete predictions which generate rigorous tests.
2. An interpretation of, not simple description, of evidence.
3. Detailed explanation of the pattern of characteristics in the autism constellation.
4. A causal account.
5. Alignment with basic scientific truths, including what we know about typical development.
6. Informed by community perspectives and priorities.

(Flecher-Watson & Happe, 2019 p.77)

[1] Calculated August 2023

An alternative Relational-Developmental-Systems paradigm discusses a modern approach to developmental theory. The emphasis is on consideration of dynamic systems, integrative and interactive processes, and how developmental changes occur across different domains (cognitive, social, emotional) (Overton, 2013). It challenges older, more linear models and proposes a new paradigm for understanding development which is useful to consider when evaluating theories.

Theories of Autism

A brief acknowledgment of historical theories is necessary, as some may still contribute to the myths and misunderstandings discussed later in this chapter. Autism was first described in 1943 and 1944 by Leo Kanner and Hans Asperger (Garcia-Villamisar & Rojahn, 2015). However, it is now widely accepted that Grunya Sukareva characterised autism almost two decades before Kenner and Asperger. Indeed, an analysis of Sukhareva's original descriptions in Russian from 1925 align them more closely to the diagnostic criteria listed in the DSM-5 (Manouilenko & Bejerot, 2015), Asperger viewed autism as an inborn difference, existing on a continuum of severity and relatively common within the population (Silberman, 2015). The clinic where Asperger worked employed a multidisciplinary team to support and educate children, adopting a life-wide approach that considered the whole child. This approach emphasized the child's strengths and talents, integrating medical and pedagogical perspectives in a person-centered manner. However, it was critiqued for lacking scientific rigor due to the absence of standardized practices (Michaels, 1935).

In contrast, Kanner characterized autism as a form of psychosis. He described affected children as having an inborn inability to establish emotional connections with others and alluded to parental involvement in their developmental difficulties. Kanner suggested that many parents of autistic children were emotionally distant, highly intellectual, and preoccupied with science, art, or literature, often engaged in cold or formal marriages. This perspective aligned with the psychoanalytic era, during which childhood mental health issues were frequently attributed to inadequate parenting, and institutionalization was a common response (Wolff, 2004). Despite documenting functional skill delays, sensory differences, and anxiety in autistic children, these features were not incorporated into early diagnostic criteria (Bettelheim, 1967; Kanner, 1949). The omission of these critical characteristics contributed to an incomplete understanding of autism and may have misdirected research and clinical practice. Notably, sensory differences were only formally recognized in diagnostic criteria with the publication of the DSM-5 in 2013—seventy years after autism was first described.

Bettelheim (1967) further perpetuated the idea that autism resulted from affective psychological trauma caused by inappropriate parenting. His book, *The Empty Fortress: Infantile Autism and the Birth of Self*, argued that autistic withdrawal stemmed from a child's psychological response to perceived threats at critical developmental stages. Working at the University of Chicago, Bettelheim claimed success in treating autistic children by removing them from their parents and providing therapeutic interventions. As a former concentration camp prisoner, he controversially likened autistic children's behaviour to that of prisoners who had "given up" in the camps. He reported, for example, that a child who did not react to a ruptured appendix demonstrated a lack of pain sensitivity similar to that of prisoners subjected to extreme cruelty. Such interpretations ignored underlying differences in development and sensory processing that had already been noted in Kanner's descriptions (Kanner, 1944), instead attributing them to affective disturbances and trauma. Over time, the emphasis on trauma and environmental influences in autism research would be subject to significant critique.

Rutter (2002) reviewed research on the role of nurturing in both typical and atypical child development between the 1950s and 1970s. While acknowledging advances in understanding, he highlighted misleading claims and criticized the period as one dominated by environmentalism, the overemphasis on environmental factors in explaining atypical development. He particularly critiqued the uncritical acceptance of environmental causation in autism research, as exemplified by the theories of Kanner (1943) and Bettelheim (1967).

Following this brief historical overview, the next section will examine theories relevant to this thesis, with a focus on cognitive, developmental, and evolutionary perspectives.

Theories of Autism: Cognitive Focus

Core cognitive theories: Theory of Mind, Executive Function and Weak Central Coherence

Shar and Frith (1983) conducted experiments comparing autistic children with neurotypical controls, assessing their performance on various visuospatial and orientation-based tasks. One such assessment, the Embedded Figures Test, required participants to identify a specific shape within a complex visual display. The results demonstrated that autistic children outperformed controls in terms of both speed and accuracy, suggesting a specific enhancement in visuospatial processing within this task. This led the researchers to propose the concept of ‘islets of ability’—distinct cognitive strengths in certain domains amidst broader cognitive impairments. However, this advantage was not observed across all tasks,

indicating that such strengths were context-dependent rather than indicative of a generalized visuospatial superiority.

Building on these findings, Shar and Frith hypothesized that autistic children possessed an enhanced ability for orientation but exhibited weaknesses in broader visual processing. They suggested that the ability to rapidly identify hidden figures stemmed from a reduced susceptibility to holistic interference, allowing autistic children to focus on local details rather than the gestalt. Despite these specific strengths, autistic children exhibited deficits in social cognition, as demonstrated by their poor performance on the False Belief Test—a key measure of Theory of Mind (ToM), or the capacity to attribute mental states to others (Baron-Cohen, Leslie, & Frith, 1985). ToM is foundational for pretend play and social development, and impairments in this domain have been widely implicated in autism research.

Further evidence supporting ToM deficits emerged from picture sequencing tasks designed to assess comprehension of different types of events. Autistic children performed comparably or better than controls on sequences depicting mechanical events but struggled significantly with those requiring an understanding of mental states (Baron-Cohen et al., 1986). This suggested that their difficulties were not rooted in a general impairment in sequencing or social interaction but rather in the ability to infer and interpret mental states—reinforcing the hypothesis that ToM impairments are a core feature of autism. It is also worth noting Milton's (2012) interpretation, something he termed the "double empathy problem", where many of the difficulties faced by autistic individuals are due to the struggles non-autistic have in understanding the thoughts, beliefs and emotions of autistic people.

Despite the explanatory power of ToM deficits, Frith and Happé (1994) identified limitations in this framework. They noted that ToM deficits could not fully account for the presence of restricted interests and a preference for sameness, or explain why approximately 20% of autistic children in the original study were able to pass ToM tasks. Furthermore, they highlighted the 'spiky profile' often observed in autism, when individuals exhibit both pronounced difficulties and isolated cognitive strengths. To address these discrepancies, they proposed an additional cognitive framework: Weak Central Coherence (WCC). Rather than framing it as a deficit, they conceptualized WCC as a cognitive style, characterized by a preference for processing local details over holistic representations. This perspective offered a broader explanation for the uneven cognitive abilities observed in autism, beyond the limitations of ToM theory.

An alternative cognitive theory is Executive Functioning Theory. Executive Functioning is a broad term that is used to describe a range of skills that guide actions and activities, (Hill

2004). These skills have been described as planning, working memory, inhibition, impulse control and other cognitive functions. Hill (2004) reviewed studies that were related to planning, mental flexibility, inhibition, and the monitoring of self. Study findings were contradictory, with difficulty identifying whether there were executive deficits in autistic children or not, and a lack of universality in studies. A later meta-analysis of executive dysfunction studies was undertaken as evidence remained mixed (Demetriou et al., 2018). Two-hundred and thirty-five studies were included and found a statistically significant result for executive dysfunction in autism, but not sub-domains. Adults showed smaller effect sizes, with the suggestion that this finding could be a result of increased maturity or use of strategies to adapt (Demetriou et al., 2018). The age range of adults included in the meta-analysis is not clear, so it remains a possibility that executive functioning may be more problematic in childhood and these difficulties decrease with age and development. In the next section, a further cognitive theory that considers cognitive style is discussed.

Theories of Autism: Perceptual Differences

Enhanced Perceptual Functioning Model

It was noted above that research studies have shown that autistic people tend to show enhanced performance in embedded figure tasks where one is required to find a shape hidden in a picture (Shah & Frith, 1983). Weak Central Coherence theory was proposed in response to enhanced performance findings in embedded figures tasks, with an islet of ability surrounded by a deficit in processing global aspects. In contrast to WCC theory, others have proposed (e.g. Mottron et al.,2006) the superior performance as a local bias within the brain due to the enhancement of processing stimuli at low-level perceptual operations. Therefore, the superior performance in processing visual tasks is due to an enhancement in one aspect of functioning, specifically, an ability to process at a local level.

Mottron et al. (2006) also critiqued the WCC theory proposal of cognitive 'styles' rather than 'deficit' as a response to papers, which showed that global aspects could be processed in some conditions. Other studies have found that superior visual performance in the autistic population is limited to the perceptual load of the stimuli (Hessels, Hooge, Snijders, & Kemner, 2014). Mottron et al. (2006) proposed that the cognitive differences between autistics and non-autistics are differences in brain organisation and presented an updated theory of The Enhanced Perceptual Functioning Model (EPF) of autism, based on findings from numerous studies (Grill-Spector & Malach, 2004; Mercier, Mottron, & Belleville, 2000; Mottron, Dawson, & Soulières, 2009; Mottron et al., 2003; Mottron et al., 2007; Ropar

& Mitchell, 2002), that highlight key differences in autistic perceptual processing (Mottron et al., 2006) and describe eight principles of autistic perception. The principles are:

Principle 1: The Default Setting of Autistic Perception is More Locally Orientated than Non-Autistic (enhanced detail perception).

Principle 2: Increased Gradient of Neural Complexity is Inversely Related to the Level of Performance in Low-Level Perceptual Tasks (diminished movement perception).

Principle 3: Early Atypical Behaviours have a Regulatory Function Towards Perceptual Input.

Principle 4: Perceptual Primary and Associative Brain Regions are Atypically Activated During Social and Non-Social Tasks.

Principle 5: Higher-Order Processing is Optimal in Autism and Mandatory in Non-Autistics

Principle 6: Perceptual Expertise Underlies Savant Syndrome.

Principle 7: Savant Syndrome is an Autistic Model for Subtyping PDDs.

Principle 8: Enhanced Functioning of Primary Perceptual Brain Regions May Account for Autistic Perceptual Atypicalities

This model is based on studies that show enhancement in perception and the early onset of behaviours that minimise sensory input (Principle 3). Further proposals (Mottron et al., 2009) considered the role of perceptual mechanisms and the development and characterisation of savant abilities. The researchers suggest that an encounter with structured material brings an autistic special interest: the material becomes associated with positive emotions and increases orientation towards similar patterns. Repetitive play is related to positive emotions, and such play tends to group objects or information, explaining the restricted, repetitive behaviours and interests associated with the diagnostic criteria (Mottron et al., 2009, 2006). The researchers also highlight that infants show a high degree of sideways glances, suggesting early adaptive behaviours to decrease sensory input. This finding suggests that superior performance and processing can lead to enhancements in some tasks and experiences that the individual finds intolerable, leading to adaptive behaviours.

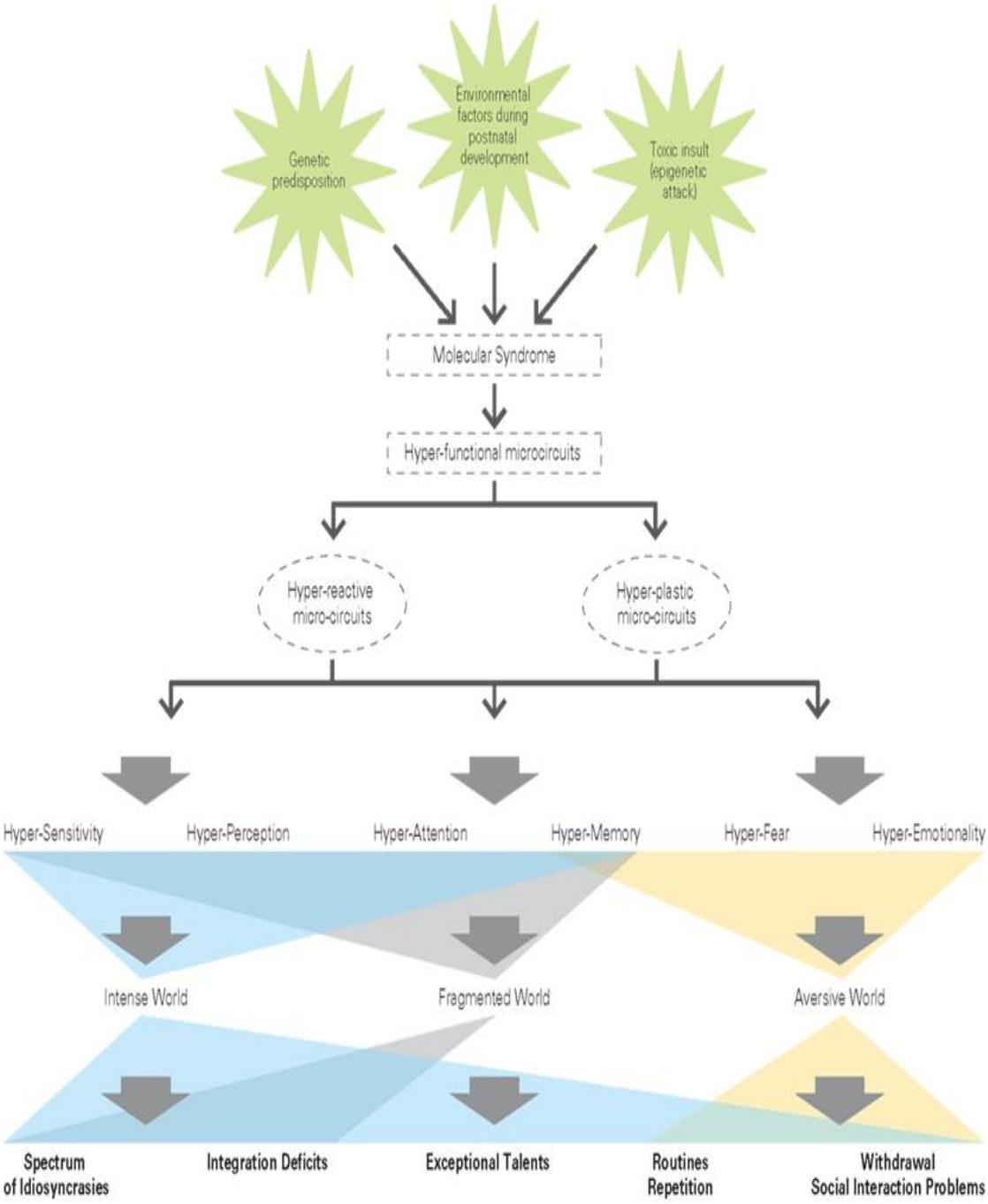
While the model explains some aspects of autism presentation and development, there are aspects of autistic presentation that are not accounted for, such as delays in language and functional skills development.

Intense World Theory

Another perceptual theory is the Intense World Theory (IWT) (Markram & Markram, 2010). The theory proposes that a genetic predisposition alongside this theory suggests that autism is characterised by hyper-functioning of local neuronal circuits that are hyper-reactive and hyper-plastic. These proposed core differences are projected to become autonomous and memory-trapped and this leads to the consequences of hyper-perception, hyper-attention, hyper-memory and hyper-emotionality. Intense World Theory suggests that autism is a poly-genetic[2], epigenetic condition that is triggered by an 'insult' and that the autistic *'pathology'* unfolds during development (Markram & Markram, 2010 p. 3). Brain hypertrophy is triggered by an epigenetic insult that leads the brain to be excessively reactive to the environment (Markram & Markram, 2010). The figure below shows the Intense World Theory and explains how hyper-reactivity leads to symptomology and autism presentation:

[2] Poly-genetic means a number of genetic sources.

Figure 1. The Intense World Theory of Autism (Markram & Markram, 2010, p.9)



Intense World Theory focuses on the neocortex and amygdala, though it is proposed that all brain regions may be involved. The development of autism is proposed to be driven by intense reactions to experiences. These lead the brain to have hyper-preference, becoming more extreme with new experiences and may be hastened by emotional

experiences and trauma. This is proposed to lead to detailed processing of fragments of the world and distancing from what becomes a painfully intense world, with the autistic child becoming trapped in a limited and secure internal world with few extremes and surprises (Markram & Markram, 2010). It is suggested that until the age of six, to minimise progression and to reverse hyper-functionality, extremes of stimuli and emotions should be avoided. It is proposed that autistic children should be provided with calm and predictable environments, with new stimuli, tasks and people being introduced carefully and removed if distress occurs. Whilst other scholars acknowledge that an overarching theory of autism would be welcome, the IWT has received criticism. There is concern about releasing a hypothesis into the public domain prematurely with little academic scrutiny, as the past has shown that this can be detrimental. Concern has also been raised regarding the proposed treatment of withdrawal of stimulation during infancy, which, if the theory is incorrect, could be detrimental to the development of cognitive, emotional and social functioning in autistic children (Remington & Frith, 2014). It could also be noted that IWT fails to account for the language delays in autism, which if a theory is comprehensive, it should do.

Development Trajectory Theories

The Social Orienting Hypothesis

The Social Orienting Hypothesis proposes that autistic infants hold less preference to social content (Dawson et al., 2004). It is proposed that the mechanism for prioritising attention to social content such as faces and voices is disrupted, leading to missed opportunities to develop language and learn social behaviours. This is based on the evidence that infants were less likely to respond to social sounds such as their name being called and from eye tracking studies that noted differences in looking patterns of adults. However, there are studies that show a generalised deficit in social orienting is not supported through eye tracking studies (Guillon, Hadjikhani, Baduel, & Rogé, 2014). Others have found that by using repeated testing for eye tracking, differences were found in the trajectory of looking patterns over time for infants who would later receive and autism diagnosis and those who did not (W. Jones & Klin, 2013).

The Social Motivation Hypothesis

A similar theory to the Social Orienting Hypothesis is the Social Motivation Hypothesis. The hypothesis is that there is an innate mechanism involved in making social information rewarding and this is either reduced or absent in autistic infants (Chevallier, Kohls, Troiani, Brodkin, & Schultz, 2012). However, this cannot be claimed universally as many autistic children and adults are motivated to engage with other people (Watts et al., 2024).

As previously discussed the Relational-Developmental-Systems paradigm discusses a modern approach to developmental theory. The emphasis is on consideration of dynamic systems, integrative and interactive processes, and how developmental changes occur across different domains (cognitive, social, emotional) (Overton, 2013) and neither the Social Orienting Hypothesis or social motivation hypothesis achieve this.

Neurodiversity Theory

Recent years have seen a rise in people within the autism community adopting the neurodiversity framework. The concept is to recognise that autism is an example of diversity in a range of possible brains, all different, with no 'normal'. The concept of neurodiversity is acceptance, with respect and dignity, and not to be pathologised.

Neurodiversity theory conceptualises neurological differences, including autism, as natural variations of human cognition rather than pathological deficits requiring normalisation. Originating in activist and scholarly discourse during the late 20th century, the term neurodiversity is widely attributed to Singer (1999), who framed neurological diversity as analogous to biodiversity and argued for the recognition of minority neurocognitive identities.

Within this framework, autism is understood not as a disorder to be "cured" but as a distinct neurotype characterised by differences in social communication, sensory processing, and patterns of cognition (Kapp et al., 2013). Neurodiversity theory challenges the dominant medical model, which positions autism primarily in terms of impairment and deficit, and instead aligns more closely with social and relational models of disability. These perspectives locate disability not solely within the individual but in the interaction between neurological difference and environments that are structured around neurotypical norms (Oliver, 1990; Milton, 2012).

A central contribution of neurodiversity theory is its critique of normative assumptions about functioning and competence. It foregrounds autistic self-advocacy and lived experience as essential sources of knowledge, arguing that historically marginalised voices should be central in shaping research, policy, and practice (Pellicano & den Houting, 2022). Relatedly, the "double empathy problem" proposed by Milton (2012) reframes social communication difficulties as reciprocal misattunements between autistic and non-autistic individuals, rather than deficits located exclusively within autistic people.

Neurodiversity also emphasises strengths-based understandings of autism, highlighting capacities such as pattern recognition, attention to detail, and innovative problem-solving (Baron-Cohen, 2017). This has led to increasing interest in neurodiversity-informed

approaches within education and employment, focusing on environmental adaptation, inclusion, and the removal of disabling barriers rather than individual remediation.

Nevertheless, neurodiversity theory is not without critique. Scholars have noted tensions between affirming autism as difference and recognising the substantial support needs experienced by some individuals, particularly those with co-occurring intellectual disabilities or complex health conditions (Jaarsma & Welin, 2012). Contemporary debates therefore emphasise the importance of integrating neurodiversity perspectives with nuanced, person-centred approaches that acknowledge both identity and support requirements.

The challenge that arises from this concept is whether children or adults should be subject to interventions to ‘normalise’ their behaviour (Baron-Cohen, 2017). Baron-Cohen (2017, himself argues that the intervention question should be neither right nor wrong, rather, the ethos and aims of the intervention should be questioned, Does this intervention aim to respect and value neurodiversity? Does this intervention aim to enable the individual to live the best life of their choosing? These are questions that recognise and respect neurodiversity and the choice and control of the individual.

In sum, neurodiversity theory represents a significant paradigm shift in autism scholarship. It reframes autism as a form of human diversity, challenges deficit-oriented models, and advocates for inclusive social structures that accommodate a wide range of neurocognitive profiles.

Evolutionary Theories

The Solitary Forager Hypothesis (Reser, 2011) has proposed that certain autistic traits would have left the autistic child and adult with favourable learning abilities and hunting and gathering skills in the ancestral environment. For example, ‘repetitive’ and ‘obsessive’ behaviours may have helped obtain food. This theory considers many autistic traits as adaptations that were complimentary to a more solitary life. The hypothesis proposes that autistic people were partially solitary, with only some traits (i.e. those that are sub-clinical) being favoured by natural selection and that cases of autism are likely due to assortative mating, where similar phenotypes mate with each other.

The Social Motivation theory (Chevallier et al., 2012) proposes that social motivation is an evolutionary adaptation that enhances fitness in collaborative environments. Pressures to collaborate lead to neuropeptides influencing social orienting, social seeking and liking and maintaining social relationships. It is proposed that early differences in social attention deprive the child of adequate social learning experiences, resulting in an imbalance of

attention to social and non-social stimuli, that further disrupts social cognition and skill development. The authors acknowledge that the theory fails to account for non-social aspects of autism, such as repetitive behaviour and enhanced abilities, however, they argue that autism may have multiple aspects and several theories may provide a comprehensive understanding.

The Extreme Imprinted Brain theory (Badcock & Crespi, 2006) is reported to be complimentary to and expanding of, the Extreme Male Brain theory (Baron-Cohen, 2002). The theory proposes that imbalances in brain development are driven by either enhanced effects of paternally imprinted genes, deficits in the effects of maternal genes, or a combination of both. This leads to the differences in development of brain regions, resulting in functional underconnectivity of brain circuitry, leading to increased local vs global processing of information and reduced central coherence.

Central to the Polyvagal theory (Porges, 2019; Porges, 2003) is the functionality of the vagus, the tenth cranial nerve, that plays a large part in the autonomic nervous system. The autonomic nervous system (ANS) is responsible for unconscious bodily functions, and the defence response. Through evolution, vertebrates developed two types of defensive behaviours, fight/flight or freeze. As mammals evolved, the ANS integrated with neural pathways that control the muscles of the head and face, which evolved into an enabler of prosocial behaviour. This includes muscles that are involved in facial expression, speaking, listening and ingestion. These are proposed to have evolved to cue other members of the species that it is safe to engage in social behaviour. This system is also able to regulate the older mechanism to initiate movement in safe contexts or change response from fear-induced defence to calm and intimate behaviours. It is proposed that this social engagement system may be decreased in autistic people, so they can detect danger, but not safety cues (Zürcher et al., 2013). A third cluster of autism symptoms that are accounted for with this theory is the involvement of the hypothalamic–pituitary–adrenal axis and immune system, which are found to be dysfunctional in autistic individuals (Angelopoulou et al., 2025). The reported potentially disordered regulation of the system is associated with autistic traits, such as lack of facial expression, poor vocal intonation, hypersensitivity to sound and a tendency to remain in defence mode (Hill et al., 2025).

This section of the chapter has reviewed some theories of autism, and it should be noted that this is not a review of all theories. Many have been proposed, but included are those that have featured prominently in research and practice and are relevant to this thesis. Key areas that need further exploration and explanation are: The heterogeneity found in the

autistic population, why do autistic individuals differ so much in strengths and challenges? How do sensory differences shape cognition and behaviour? How does autism present differently in females? Developmental trajectories exploration should consider how autistic traits change over time. It could also be proposed that Strengths-based approaches may be more helpful, and therefore how can future theories better account for autistic strengths rather than just deficits?

Autism & Mental Health

This chapter aims to further understand historical and current influences on how autism is understood and supported and this should include co-morbid conditions that may be taken into account when developing an intervention. Dillenburger et al. (2015) found that autistic children had higher Attention Deficit Hyperactivity Disorder rates, behavioural issues, lower overall happiness scores, and reluctance to attend school. The children also experienced higher levels of bullying and social isolation. Autistic children frequently experience one or more comorbid conditions, and a number of these are psychiatric in nature (Close, Lee, Kaufmann, & Zimmerman, 2012; Gadow, Devincent, & Schneider, 2008; Garcia-Villamisar & Rojahn, 2015; S. E. Levy et al., 2010; Mattila et al., 2010). A range of psychiatric conditions has been identified, with the most commonly occurring conditions being anxiety, depression and behavioural disorders and these will be the focus of the following sections. A recent study aimed to examine the co-morbidities and complex needs of autistic and non-autistic young people. The researcher reported that the statistically significant issues that were associated with autistic young people were those of community, attainment and deemed to be a child in need. The autistic young people also scored statistically significantly more items in the complexity/contextual/educational factors, while co-morbidities included anxiety, self-care tasks, behavioural issues and peer relationship difficulties (Thompson et al., 2023).

Anxiety

Anxiety rates are high in the autistic population. A study found that parents reported their children experienced common childhood anxieties, such as being rejected, being different, or being let down, and autism-related anxieties. The latter was related to sensory worries, auditory anxieties, novelty and uncertainty (Lau et al., 2020). Anxiety is discussed in depth in the Autistic Development Theory chapter and will not therefore be reviewed in this chapter.

Depression

A study by Strang et al. (2012) found that of the 95 autistic children aged 6 to 18 who participated, 30% had depressive symptoms within the clinical range of depression, and 40% presented with borderline levels of symptoms. The researchers suggest that autistic children and adolescents are at an increased risk of depression and or anxiety regardless of IQ, age

or autism symptomology when contrasted to standardization sample norms. A review attempting to find prevalence rates of depression in autistic children found rates ranged from 1.4% to 38% between studies (Magnuson & Constantino, 2011). The researchers note that the disparity in prevalence for depression was more significant than any other comorbid condition within the studies reviewed, highlighting the difficulty that researchers and practitioners may have identifying depression within the population.

The DSM-5 requires five or more of the symptoms listed below to be present within the previous two-week period to obtain a diagnosis of a major depressive episode:

- Depressed mood
- Loss of interest or pleasure
- Appetite or weight changes
- Sleep difficulties
- Psychomotor agitation or retardation
- Fatigue or loss of energy
- Diminished ability to think or concentrate
- Feelings of worthlessness or excessive guilt
- Suicidality

(Tolentino & Schmidt, 2018, p. 1)

Magnuson and Constantino (2011) suggest that many autistic children have difficulty identifying and expressing how they feel, which can lead to difficulty in identifying and diagnosing a depressed state. In these instances, there is a reliance on observable behaviours and parental reports (Magnuson & Constantino, 2011). The documented observable behaviours are said to include increased sadness, crying, negative affect and apathy. Other differences include increased sleep, weight changes, decreased performance and loss of skills. Additionally, there can be an increase in self-injurious behaviour, which is reported to decrease upon treatment for depression.

Contributing to difficulty identifying depression within the autistic population is the overlap between behavioural changes associated with a depressed state and autism presentation. It was previously thought that “higher-functioning children” could have insight into their differences, resulting in a negative self-perception alongside decreased self-worth. Vickerstaff et al. (2007) found that higher ability led to an increased understanding of the

condition, leading, in turn, to a perception of lower social competence and higher rates of depression. In contrast, Strang et al. (2012) found no relationship between emotional symptoms and cognitive ability. The risk of depression may not be as simple as cognitive ability alone and may be increased by other factors. The impact of other comorbid conditions, such as ADHD, has been shown to increase the risk of depression and the severity of depression. Gadow et al. (2012) found that whilst there was an increased risk of autistic boys developing depression, the risk increased when there was a second comorbid condition, such as ADHD. They also found that when depression occurred in children with two or more conditions, the symptoms were more significant than in children without a comorbid condition. This may be due to the greater difficulty that the children face in day-to-day life when they have multiple conditions.

Peer relationships seem to be significant contributors to developing depression, with peer rejection linked to depression (Wright & Wachs, 2019). A study with college students found a link between higher autistic traits and perceived external locus of control, contributing to self-perceived helplessness (Kanne, Christ & Reiersen, 2009). Barnhill (2001) describes the variables of high IQ and “high-functioning autism”. The suggestion is that autistic children presenting with increased functioning levels may blame themselves for social failure, such as for lack of personal ability, rather than other explanations such as chance. The self-perceived lack of ability and blame for social failure is suggested to result in increased depressive symptoms. Magnus et al. (2011) suggest that learned helplessness is involved in the development of depression. This raises an essential issue for consideration in the development of interventions. It would be essential to ensure that interventions address these issues by developing positive self-appraisal and self-perception and decreasing learned helplessness.

The development of depression in autistic children and adolescents has also been linked with the broader family. Both depression and anxiety are observed in family members of autistic children, with reported rates higher than is usually found in the general population (Brimacombe, Xue Ming, & Parikh, 2007). A history of family depression tends to be significant in depressed autistic children (Mazefsky, Folstein, & Lainhart, 2008), and there is an association between maternal depression and autism (Daniels et al., 2008). Daniels et al. (2008) also found that parents are more likely to have been hospitalised for mental illness than parents in the control group. Building on previous research, Mazefsky et al (2010) conducted a study examining the relationship between depression and anxiety in high-functioning adolescents with ASD (an unofficial term used by the authors to designate autistic adolescents with average-high IQs, strong language skills and lower support needs). They found that 33% of autistic children met the criteria for a history of depressive disorder.

The study found a relationship between the mother's symptoms of depression, anxiety, phobic anxiety, hostility and interpersonal sensitivity, and comorbid depression and anxiety within the children. Specifically, maternal measures of anxiety were predictors of comorbid depression in children. Again, it is not clear whether the mothers are developing anxiety because their children are depressed or if the mother's anxieties contribute to the development of the child's depression. While there are limitations to the study and further investigation is needed, the relationship between parental and child mental health provides further evidence for the need for family interventions, enhancing life and improving outcomes for all family members.

Depression has also been linked to suicidal thoughts, attempts and completed suicides within the population with ASD. In an online survey, Paquette-Smith et al. (2014) questioned 50 autistic adults and found 35% had attempted suicide in the past. This compares to the rate of 4.6% in the general population. This extremely high rate of attempted suicide within even a small sample is alarming and gives rise to concern. However, it is not clear that the rate is fully reflective of the general ASD population. It is unclear how potential participants were informed at the advertising stage that the study's focus was mental health. If this is the case, adults who had not experienced mental health difficulties may have been put off participating and decided not to engage. In addition to this, study participants were recruited through autism support organisations and websites. It could be argued that adults who are not experiencing mental health difficulty are less likely to be accessing these services, and therefore not be aware of the study. The study found that those who had previously attempted suicide had a history of depression and reported more challenges with communication and attention-switching. This suggests that the more significant communication difficulties led to people facing greater challenges in communicating their feelings and mental health difficulties. Taking into account the general population group. The factors that were reported to be associated with feelings of anxiety were a high level of self-focus, worries about everyday events with rumination lasting over ten minutes. It could be postulated that difficulty switching attention leads people to 'get stuck' in internalised thoughts that they find difficult to communicate to others or make sense of them, which leads to a self-perpetuating cycle.

Mental Health Access

It is not uncommon for autistic adults to be misdiagnosed. In the National Development Team for Inclusion (NDTi) report (2012) on reasonable adjustment within mental health services for people with autism and people with learning difficulties, there are examples of misdiagnosis, for example, an individual being labelled a sociopath with schizophrenia and paranoid tendencies whilst waiting for two years for an autism assessment (NdTi, 2012).

They reported that the overwhelming message was the failure of services to meet their legal obligations to ensure equal access to services. The report highlighted that adjustments were needed in many areas, including the physical environment, communication, adjusting treatments and interventions, and further staff training. The report highlighted good practices on which to build; however, there is a need to advance skills for autistic people to be appropriately supported. It appears that many adults do not fit into the existing provision, and their needs are not being met whilst they face delays and inappropriate support. More recently, an NHS guidance report (England, 2023) stated that the proportion of adults being diagnosed with autism has risen significantly, and the growth of diagnosis is accelerating. The report also states that between March 2017 and August 2023, there was a 7.3% increase in autistic adults as mental health inpatients, and in this time frame, a 51.3% increase in autistic inpatients without a learning disability (England, 2023). This may be indicative that services may be identifying and diagnosing autism in adults more than has previously been the case, however, there appears to be a problem with meeting their needs post-diagnosis.

A qualitative study with mothers of autistic children aged 11 to 15 years, who had been referred for mental health issues undertook semi-structured interviews. They reported that the themes generated were the psychological impact on the caregiver, negative experiences accessing mental health provision, and a breakdown in the relationship with professionals. Importantly, they also reported that managing the impact of their children's mental health, including self-harm and suicidal ideation, commonly led to feelings of isolation, self-blame, guilt and powerlessness which impacted negatively on the mothers' mental health (Jackson, Keville, & Ludlow, 2020).

Raja et al. (2011) reported difficulty undertaking assessments of the risk of suicide with these patients. The two patients who died by suicide were deemed to be not at risk in the preceding months. They suggest that there are clinical variables that may mislead clinicians in autistic patients. There is also a suggestion that typical symptoms are possibly hidden due to the impact of ASD, and the difficulty communicating and interacting can mislead clinicians to consider the person to be calm and stable. There is a significant cause for concern with the high rates of suicide and attempted suicide within the autistic population (Harper, Smith, Cassidy, et al., 2019). Furthermore, the concern is raised by the reported difficulty in assessing the risk of suicide within this population. A study of deaths by suicide of 372 coroner cases in two regions of the UK, explored the prevalence of autism, both diagnosed and undiagnosed. The study found that when taking into account diagnosed individuals, and those who showed autistic traits who were not officially diagnosed, a prevalence rate of 41.4% in this particular study. The researchers concluded that high

autistic traits were significantly over-represented in those who die by suicide (Cassidy et al., 2022).

There is evidence of a higher degree of mental health problems in the autistic population, and the next section considers access to mental health support for autistic children. A systematic review of qualitative research concerned with gaining a greater understanding of parental experiences supporting their autistic child's access to healthcare services has been undertaken. The study included 12 studies and resulted in four categories of synthesised findings; parents reporting challenges accessing and using mainstream health services for their autistic child; due to a lack of understanding, not having a voice, lack of communication and lack of understanding from healthcare providers (Boshoff et al., 2021).

As previously discussed, a solid understanding of autism is crucial if support and intervention are to be successful, as is the ability to adapt communication style and methodology when working with autistic children.

Jackson et al., (2020) highlight the difficulty accessing support when autistic children need mental health intervention, leading to a knock-on effect of mothers reporting their mental health being affected. It appears the current provision for autistic children who are experiencing mental health difficulties does not appear to be meeting needs. As is the case with the adult provision, there is a need for staff training and appropriate and timely support to enable children to overcome their difficulties and live rewarding lives. The following section reviews the mental health interventions that are offered to autistic children.

Mental Health Interventions

When children access services, a range of treatments and interventions can be used, either behavioural or pharmacological. The over-medication of people with intellectual disability and autism is of concern, and the NHS is currently funding a programme, Stop the Over-medication of People with Intellectual Disability and Autism (STOMP) (Branford, Gerrard, Saleem, Shaw, & Webster, 2019). Murray et al. (2014) investigated pharmacological treatments in primary care using the medical records of 5,651 patients under 25 years in the UK. As there are no psychotropic drugs approved for ASD in the UK and no practice guidelines, they aimed to find the pattern of prescribing in the population. Nine categories of drugs were defined; these are presented in Table 2.

Table 1. Prescribing Details of an Autistic Cohort 1999-2008 (Murray et al., 2013)

Drug Group	% of autistic patients prescribed
Stimulants	27.5
Anti-depressants	21.6
Anti-psychotics & and mood stabilisers	25.6
Benzodiazepines	22
Clonidine	1.9
Sleep medication	34
Beta-blockers	2.2
Other	4.8
Anti-parkinsonism	2.7

Public Health England (Glover et al., 2015) undertook a study into the prescribing of drugs acting on the central nervous system for adults and children with learning disabilities and autistic individuals. They reported that for autistic people without learning difficulties, those who were under 16 years, 1.5% were prescribed antipsychotics, 0.2% of drugs for managing mania and hyper-mania, 1.1% antidepressants, 3.2% hypnotics, and 0.1% anxiolytics. Rates for adults were antipsychotics at 8.2%, mania management at 3.5%, antidepressants at 17%, hypnotics at 2.1% and anxiolytics at 1.8%. The report also states that prescribing was long-term in 90% of patients. The proportion of autistic adults being prescribed more than one drug was 30.3%, and 13.6% of autistic children.

The report claimed that in the categories studied the use in young autistic people was not for use for treatment of conditions the drug is intended for, but in the hope that drugs would assist with behaviour management that carers deem problematic (Glover et al., 2015). However, the report does claim that studies have found risperidone to be effective in treating behaviour disorders in autistic children.

An investigation into the prescribing patterns across the world for autism co-morbidity treatments from 2007-2012, found that the highest prescription rates were in Western Europe and the lowest in Asian countries, such as Saudi Arabia, Pakistan, Turkey and Indonesia. The researchers reported that co-morbidity treatment in most countries was risperidone, although antidepressants and antiepileptic drugs were also frequently prescribed (Wong et al., 2014) The use of medication for autistic children and adults is of concern, and it is pertinent to consider approaches other than medication to treat mental health challenges.

There is growing evidence that cognitive behaviour therapy (CBT) effectively treats anxiety in autistic children (Bemmer et al., 2021; Scarpa & Reyes, 2011; F J A Van Steensel & Bögels, 2015). CBT is a talking therapy that aims to address faulty thinking patterns and underlying beliefs (Beck, 2015). People respond to events through conscious thoughts and their underlying representations and beliefs. Beck (2015) describes the process of automatic thoughts following the processes below:

Stimuli > Automatic Thought > Affect > Behaviour

Situation > Negative Thought > Negative Affect > Response

Beck (2015)

Additionally, CBT concerns itself with 'faulty' thinking, including arbitrary influences, selective abstraction, over-generalisations, maximisation, minimisation, personalisation and dichotomous thinking. These are challenged by using the following strategy (Beck, 2015):

- Education.
- Self-assessment.
- Teaching that personal meanings associated with thoughts are what makes them uncomfortable.
- Learning to let thoughts go.
- Teaching clients to generate two alternative ways of thinking about the situation.

A meta-analysis of eight randomised controlled trials involving 469 autistic patients, 252 treatments, and 217 comparisons (Sukhodolsky, Bloch, Panza, & Reichow, 2013) found that parent and clinician ratings led to statistically significant changes which were similar to those found in typically developing children of decreased parent and clinician-reported anxiety. However, these were not mirrored in the child ratings. While it is not unusual for

discrepancies to be found with multi-informants, they suggested that there may be various explanations for the differences. Parents may find that they are more concerned by the child's anxiety, hence higher pre-treatment reporting Alternatively, the parents may consider that the intervention is more helpful than the children consider it to be and see subsequent behaviour changes as anxiety reduction when the subjective experience does not reflect this (Sukhodolsky et al, 2013).

Drahota et al. (2011) assessed the effect of modifying a CBT programme for children called 'Building Confidence' to use with autistic children aged 7-11 years. The modifications were designed to support adaptive skills, social skills, restrictive and repetitive interests, poor motivation, attention and behaviour problems. They suggested a link between anxiety and poor daily living skills and sought to address this development aspect with the programme. Therapists undertook 16 weekly sessions of 90 minutes, with 60 minutes of this time with the parents and 30 minutes with the children. The study found an increase in daily living skills, decreased parental over-involvement and a correlation between an increase in daily living skills and a decrease in anxiety. They found that the parents in the treatment group reported increases in their children's daily living skills, which were maintained over three months. There was also a reduction in parental over-responsiveness and a correlation between reduced anxiety and increases in daily living scores. Drahota et al. (2011) suggest that age, the severity of autism (the authors' designation), intelligence and memory may also play a part in the continuation of poor daily living skills in autistic children. Drahota et al. (2011) suggest that parental factors may also play a part in the delay of daily living skills, with parental motivation, experiences, belief in the treatment, and adherence to the programme, being suggested contributing factors.

Parental belief about a treatment's credibility has been associated with parental motivation to perform techniques, while expectations about outcomes are associated with treatment adherence (Nock, Ferriter, & Holmberg, 2007). This highlights the need to ensure that parents understand how interventions can lead to positive change to motivate them to support adherence in daily life. While Drahota et al's (2011) outcomes are encouraging, the programme is intensive, requiring 16, 90-minute sessions by a trained professional. As previously discussed, access to mental health services is highly restricted, with many families unable to access such a provision. Funding challenges combined with such an intensive programme are likely to lead to commissioners not favouring programmes such as this due to prohibitive costs.

A further cognitive behaviour programme called 'Exploring Feelings' (McConachie et al., 2014) was adapted for use in the UK for use with a population of 32 children aged

between 9 – 13 years. The researchers also involved parents, as previous research had highlighted that parental involvement led to enhanced outcomes. Seventeen families took part in 7, 2-hour long group sessions, with separate parents and children groups. All parents in the treatment group who had not previously attended CBT sessions reported that the group had helped reduce their child's anxiety. His study found that 29.4% of children were 'much' or 'very much' improved compared to 7.1% in the waiting list control group, and 76% of those participating had some reduction in the severity of their anxiety disorder. The researchers highlighted the importance of interventions to include parents to support their children using their strategies and model behaviours in daily life.

A systematic review has considered both published and unpublished randomised trials of interventions for mental health conditions in autistic people and concluded that evidence indicated uncertainty of the effects of different interventions, and that some form of Cognitive Behavioural therapy may decrease anxiety and depression scores in autistic children and adults (Linden et al., 2023). Spek et al. (2013) undertook a further interesting study that adapted the 'Mindfulness-Based Cognitive Therapy' protocol (Segal, Teasdale, Williams, & Gemar, 2002). They removed the cognition aspect of the programme to ensure that participants were able to access the programme. Twenty autistic adults participated in the 8-weekly group session. Briefly, the focus of the eight sessions was:

Week 1: Rationale and programme content. Mindful eating exercise and body scan (paying attention to sensations in various parts of their body)

Week 2: Practice body scan. Mindful breathing and discussion regarding home practice

Week 3: Discussion of home practice. Information of physical reactions to stress. Mindful walking and a yoga exercise

Week 4: Sitting meditation focusing on breathing and body sensations and discussion on home practice

Week 5: Sitting meditation focusing on breathing and body sensations and sounds, discussion of home practice

Week 6: Sitting meditation. Psycho-education regarding rumination and autism

Week 7: Sitting meditation, home practice discussion and short breathing meditation

Week 8: Sitting meditation, movement exercise. Home practice discussion and short movement exercise

Week 9: Body scan, movement exercise. Evaluation of home practice. Discussion of experiences over the weeks. Participants chose meditation

They found a reduction in anxiety, depression and rumination, alongside an increase in a positive affect. This was the first controlled trial of using mindfulness-based therapy with autistic adults, and the researchers suggested that the anxiety reduction could be due to the reduction in rumination. Another study considered mothers of autistic children and the effectiveness of mindfulness cognitive therapy on their happiness and the ability to tolerate ambiguity. The study found that mindfulness-based cognitive therapy was effective in increasing happiness and ambiguity tolerance and the effect lasted over time (Valizadeh & Ahmadi, 2023). However, as Harnett and Dawe (2012) describe, mindfulness pays attention to the moment, including bodily sensations. Paying more attention to their sensations could be counter-productive and create, rather than decrease anxiety in the wrong context. When adapting an existing intervention for use with autistic young people, careful consideration would need to be made regarding such exercises and the potential impact on the person. Appropriate adaptions or exclusions should be made according to perceived reasonable adjustments.

The high levels of comorbid mental health difficulties faced by children and families show a clear need to develop interventions that aim to decrease anxiety, decrease the possibility of depression, and develop daily living skills.

Myths of Autism

It is widely accepted that our understanding of autism is incomplete, and despite years of research, a unifying theory or model of autism has yet to emerge (Waterhouse, 2013), even though some claim to be comprehensive. For example, the Pathogenetic Triad framework (Sarovic, 2021), claims to be comprehensive, yet fails to account for the sensory differences that are reported by autistic people and subsequently, the theory does not stand up to evaluation when the theory is considered in the context of autistic peoples lived experience. The wide variation in symptomology or heterogeneity of autism is partly responsible for the lack of research progress (Waterhouse, 2013). What has emerged is that when theories are debunked, abandoned or even found to be fraudulent, they may still leave their legacy on the broader community. Focus groups have been used to identify myths associated with autistic people (John, Knott, Harvey, & Knott, 2018). Seven emerged, and these were ***all*** autistic people:

- *Are disinterested in social relationships*
- *Do not like to be touched*

- *Are introverts*
- *They are unable to notice social rejection*
- *Have an exceptional talent or savant skill*
- *Are dangerous*
- *Are mad*

(John et al., 2018 p.12)

A publication identified myths and misconceptions and their origins and the impact that they can have on the public and the autistic community (Bennett, Webster, Goodall, & Rowland, 2018). The myths identified were regarding the perceived autism epidemic; a link to vaccinations; 'refrigerator mothers'; autism can be cured or outgrown; savant syndrome; myths of social communication and empathy; autism is a behavioural or mental disorder; and that autistic people do not want friends or sex (Bennett et al., 2018). A range of origins of these myths was reported, such as previous research or theories, books, how autism was previously classified, films and other media representations (Bennett et al., 2018). An example of this is the 'refrigerator mother' myth due to the long-debunked research and theory of Bettlehiem (Bettelheim, 1967) as autism is a childhood psychosis due to cold unattached mothers.

Other myths appear to have no direct origin and are thought to be formed by several factors. Autistic people who do not want sex are one example of the latter. A combination of factors, such as historically being viewed as incapable of rearing children, the sexuality of disabled people being discouraged in care settings, while more independent autistic adults were historically viewed as sexual deviants, are thought to be factors that are involved (M. Bennett et al., 2018). It is also suggested that the concentration of research on children and adolescents leads to impressions of perpetual childlike individuals. It is suggested that parents who cannot envisage their child maturing into sexually active adults perpetuate these myths (M. Bennett et al., 2018).

Myths that help create ever more complexity around autism have been found to cause stigmatisation and impact how autistic people are treated (John et al., 2018). The impact of myths is not to be underestimated; they can also be dangerous to children's health and wellbeing.

For example, vaccines and mercury were reported by Rimland as being associated with autism (Rimland, 2000) though this has not been supported by studies (Gil-Hernández et al., 2020). However, Rimland's claims have led to the widespread use of chelation therapy

to remove heavy metals from cells. There are no randomised controls for this therapy and cases of cardiac arrest have been reported, and is therefore not recommended for use with autistic individuals (Hangul & Tufan, 2022).

The ‘refrigerator mother’ theory (Bettelheim, 1967) has been debunked and abandoned for decades, yet holding therapy, the intervention to treat the child remains. However, despite documentaries showing distressed children resisting these experiences and screaming and crying, the practice continues and has also led to child deaths (Mercer, 2014).

The fundamental lack of understanding of what autism is will inevitability lead to challenges in appropriately supporting autistic children and adults. The lack of clarity may also lead some desperate parents to interventions that may be harmful to children. The review of theories of autism has highlighted how researchers have historically been influenced by the prevailing paradigm, their discipline or quest to find a deficit. These factors have led to abandoned theories and a legacy of myths and misconceptions, as has been briefly described in this section.

Interventions have shown that early support for children is beneficial and has a lasting impact (Matthews et al., 2018), but none of the interventions to date aim to develop children's resilience and decrease mental health problems. Interventions for autistic children have often trained parents to facilitate the intervention or use the strategies in daily life. The following section reviews this method of providing autism interventions.

Parents As Intervention Facilitators

It has been shown that there is a relationship between the child's mental health and the parents (Piro-Gambetti et al., 2023; Read & Schofield, 2010; Samadi, McConkey, & Kelly, 2013). Mental health interventions that include parents are more effective, and it is beneficial for parents to participate in such interventions (Drahota et al., 2011). Additionally, learning experiences would need to continue post-intervention; therefore, parents should be enabled to undertake strategies with their children in daily life. It has been suggested that parent training should be included in programmes to enable learning in naturalistic settings, and less structured interventions lead to faster learning. Additionally, they lead children to have higher levels of positive affect and engage in less avoidant and disruptive behaviour, (Grofer Klinger, Ence, & Meyer, 2013). One study (Reaven, Blakeley-Smith, Leuthe, Moody, & Hepburn, 2012) taught parents how to coach their child in the protocol in their CBT programme 'Face Your Fears'. They found that this helped parents to understand their child's behaviour better and reduce fears. Utilising this type of model, a parenting

programme, would have the additional benefits of being more highly accessible and cost-effective than those that professionals facilitate.

The biggest, and most widely used intervention in the UK is PACT. Paediatric Autism Communication Therapy (PACT) is a manualised, evidence-based intervention designed to support social communication development in autistic children through parent-mediated interaction strategies. Developed in the United Kingdom by Green, Charman, McConachie and colleagues, PACT is grounded in developmental and social-pragmatic theories of communication, emphasising the central role of early dyadic interaction in shaping social and linguistic development (Green et al., 2010).

PACT is distinctive in its focus on enhancing parental responsiveness to the child's communicative behaviours. Delivered typically over a series of structured sessions, the intervention involves trained therapists using video-feedback techniques to support parents in recognising and responding contingently to their child's communication signals. This approach aims to increase synchrony and shared attention within parent–child interactions, thereby facilitating the development of social communication capacities (Aldred et al., 2004; Green et al., 2010).

The theoretical underpinning of PACT aligns with transactional models of development, which conceptualise child development as emerging from dynamic interactions between the child and their social environment. Within this framework, autistic children's differences in attention, social orientation, and communicative signalling may disrupt typical interactional patterns; PACT seeks to modify the interactional environment—specifically, caregiver behaviour—rather than directly attempting to remediate the child's characteristics (Green & Garg, 2018). This positioning distinguishes PACT from more didactic or behaviourally driven interventions, focusing instead on scaffolding naturally occurring communication within everyday contexts.

Empirical evidence for PACT is robust, particularly in relation to improvements in proximal outcomes such as parent–child interaction quality and child social communication behaviours. A landmark randomised controlled trial by Green et al. (2010) demonstrated that children receiving PACT showed significant improvements in parent synchrony and child communicative initiations compared to treatment-as-usual. Importantly, subsequent long-term follow-up of this cohort indicated sustained reductions in autism symptom severity over time, suggesting that changes in early interaction patterns may have enduring developmental effects (Pickles et al., 2016).

However, the evidence base also indicates that PACT's effects are more pronounced in interactional and communicative domains than in broader cognitive or adaptive functioning

outcomes. This has led to ongoing discussion regarding the scope and limits of parent-mediated interventions, particularly for children with more complex support needs or co-occurring conditions (Green & Garg, 2018). Furthermore, debates within autism research—particularly those informed by neurodiversity perspectives—have raised critical questions about how outcomes are conceptualised, including the extent to which reductions in "symptom severity" reflect meaningful improvements in quality of life from the perspective of autistic individuals themselves (Pellicano & den Houting, 2022).

Another notable strength of PACT is its adaptability across cultural and service contexts. Variants of the intervention, including PACT-G (a group-based format) and adaptations for different healthcare systems, reflect efforts to increase accessibility and scalability (Green & Garg, 2018). Nevertheless, implementation requires trained practitioners and sustained parental engagement, which may present barriers in under-resourced settings.

In summary, PACT represents a significant contribution to early autism intervention, offering a theoretically grounded and empirically supported approach centred on enhancing caregiver–child interaction. Its emphasis on relational processes, parental agency, and naturalistic communication aligns with broader shifts in the field toward more contextually embedded and family-focused models of support. At the same time, critical engagement with its assumptions and outcome measures remains essential, particularly in light of evolving perspectives within autism research and advocacy.

Autism interventions targeted towards parents providing the intervention have gained significant attention in recent years due to their potential to enhance developmental outcomes for autistic children (Martin et al., 2019). Parent-mediated interventions empower caregivers by equipping them with strategies to support their child's communication, social, and behavioural development in naturalistic settings. These interventions are grounded in various theoretical frameworks, including behavioural, developmental, and cognitive approaches. A distinction needs to be made between parent-mediated interventions that support parents to provide the intervention to their child and interventions that are targeted towards parents. This section considers the parent-mediated interventions.

One widely studied intervention is the Parent-Mediated Early Start Denver Model (P-ESDM), which integrates behavioural and developmental strategies to promote social engagement and language skills (Rogers et al., 2012). Research indicates that P-ESDM can lead to improvements in social communication and adaptive behaviour, particularly when implemented consistently by trained parents (Dawson et al., 2010). However, challenges such as variations in parental adherence and the need for extensive training have been highlighted as potential limitations.

Another intervention is the Hanen Program, specifically the "More Than Words" program, which is designed to enhance communication in autistic children by coaching parents in responsive interaction techniques (Sussman, 1999). Studies suggest that this intervention can improve parent-child interactions and facilitate language development, although effectiveness varies depending on individual child characteristics and parental engagement levels (Carter et al., 2011).

Parent training in Applied Behaviour Analysis (ABA) is also a commonly utilized approach. ABA-based interventions teach parents structured techniques to reinforce desirable behaviours and reduce challenging behaviours through positive reinforcement (Lovaas, 1987). While ABA has demonstrated efficacy in improving communication and social skills, it has also faced criticism regarding its intensity and ethical concerns over its impact on autistic identity (Bottema-Beutel et al., 2021).

In the United Kingdom the NAS Early Bird and Barnados Cygnet programmes have been developed.

NAS Earlybird

The NAS EarlyBird programme is a psychoeducational, group-based intervention for parents, developed in the United Kingdom (Zakirova-Engstrand et al., 2023). The programme provides three months of post-diagnosis support for parents of autistic children under five years old. Its primary aim is to enhance autistic children’s social and communication skills while reducing problematic behaviour through parental education on autism, aiming to improve confidence and competence in parenting an autistic child.

Parents participate in structured group sessions led by trained facilitators, to provide training on autism, communication strategies and behaviour management. There is an emphasis on peer support and sharing experiences. Additionally, facilitators conduct home visits to observe parent-child interactions, recording these sessions for feedback during group discussions (Zakirova-Engstrand et al., 2023).

Evaluation studies of the EarlyBird programme have reported that both parents and facilitators hold positive views of the intervention, with pre- and post-outcome measures indicating positive changes. However, researchers noted that participant recruitment posed a challenge, highlighting the need for strategies to improve enrolment in future iterations (Palmer et al., 2019). It can be postulated that recruitment difficulties may stem from the programme’s three-month duration, which could be a significant commitment for families already managing multiple demands on their time and resources. The provision of the

programme is dependent on local provision with most programmes being funded by local authorities which may lead to limited accessibility.

Barnardo's Cygnet

Cygnet is a programme for parent and carers of autistic children aged five to eighteen, presented to groups over six three-hour sessions aiming to work towards behaviour management of autistic children. Cygnet aims to increase parents understanding of autism, how autistic children experience the world, what leads to particular behaviours and help parents with strategies to use with their children to support behaviour, play and communication (Stuttard, Beresford, Clarke, Beecham, & Morris, 2016). A strength of the Cygnet programme is that it covers a broad age-range of children and may be accessed in person or online and encourages peer support.

The parent-mediated Earlybird and Cygnet are both psychoeducational group-based interventions both designed to support parental understanding of autism and the use of strategies to support the development and behaviour of their children. The evaluations of both are limited and therefore evidence for efficacy is limited. However, both have reported outcome of parental positive experiences (Palmer et al., 2019; Stuttard et al., 2016). In contrast, TEACCH and ABA often involve close collaboration with families and educators.

Both NAS Earlybird and Barnardo's Cygnet were developed many years ago, when the prevalence of autism was lower than it is currently. This increase in children identified as autistic leads more families with a need for support from local authorities. The uptake of Earlybird and Cygnet by local authorities or other organisations may be impacted on by the intense resources required to provide these programmes to parents and lead to prohibitive costs. Additionally, the extensive time commitment expected from parents may also lead to parents not being able to access them due to work and/or family commitments.

Parents and children may benefit from parent-mediated interventions and psychoeducational programmes. However, the current constraints of parental time pressure and local authority budgetary pressures may inform programme planners that interventions should be as time limited as is possible.

Additionally, mindfulness-based interventions for parents, such as Acceptance and Commitment Therapy (ACT), have been explored as a means to enhance parental well-being and reduce stress associated with caregiving (Blackledge & Hayes, 2006). Research indicates that parental stress and mental health can significantly influence intervention effectiveness, highlighting the need for holistic support systems (Weiss et al., 2013).

Despite the promise of parent-mediated interventions, barriers such as socioeconomic disparities, accessibility of training, and cultural considerations remain critical factors influencing their implementation and effectiveness. Future research should focus on developing scalable, culturally sensitive models to ensure equitable access to effective interventions.

The review of the current literature leads to a compelling case for an intervention to enhance autistic young people and their family's well-being. Two studies undertaken by Waters (2015) found that authoritative and strength-based parenting contributed to life satisfaction in adolescence. Furthermore, the degree to which parents were aware of their child's strengths was enhanced, as was the degree to which parents encouraged the child to use their strengths (Waters, 2015). A study with families of adolescents aged 11 to 18 years, found that strengths-based parenting had a positive impact on the young peoples' self-esteem. Further to this, they found that resilience is positively related to young people's self-esteem in the study (Ningrum, Supriyadi, & Utami, 2022)These findings suggest that a strengths-based parenting programme may enhance well-being and outcomes for autistic children and their families. Adaptions or inclusions to current interventions would need to include parents as coaches (Grofer Klinger et al., 2013; Reaven et al., 2012), the inclusion of functional skill development (Drahota et al., 2013, 2011) and careful consideration of autism and how to appropriately adapt wellbeing interventions for the population (Spek, van Ham, 2013).

Summary

The literature review has discussed the main theories of autism since the identification of autism as a condition. There is a debate around what autism is and what leads to the wide-ranging outcomes for autistic children and adults. This lack of understanding, alongside myths and misunderstanding, may lead to ill-informed or misdirected support, which may in turn play a part in the population's heterogeneity and poor outcomes (Dillenburger et al., 2015). Additionally, the myths and misconceptions may ill-inform autistic people about themselves. For example, autistic individuals may be told they have no empathy, are not good in social situations. What would be the degree of confusion to an individual if they are told these things about themselves, and it does not ring true for their own lived experience? These issues may impact the outcomes and mental well-being of autistic people.

The theories have led to interventions that, in some cases, have been systematically evaluated and show decreases in autistic-type behaviours and skill gains, though most require significant input from trained practitioners. Several theories and interventions remain

controversial (Kupferstein, 2020) and have led to divides and debates within the community, and some report a loss of trust in research and the aims of interventions (Milton, 2014).

This chapter has shown that there is a need for a non-age defined, flexible intervention that focuses on strength-based development and increasing well-being for autistic children and their families.

However, as autism understanding is incomplete, the starting point for a new intervention should be to attempt to develop a more complete explanation. This may consider the current evidence that is available to find if it may be synthesised into a more comprehensive explanation.

The next chapter considers why autism occurs and what region of the brain may be involved. The chapter offers an evolutionary theory of autism, the Adapted Phenotype Theory, using the evidence that is currently available, to provide a plausible explanation for autism being an ancient epigenetic adaption in response to stress during pregnancy. Following on from this, the second part of the chapter offers Autistic Development Theory, considers how modernity impacts the development of the features of autism and factors that may influence development.

CHAPTER THREE

Autism Through an Evolutionary and Complex Systems Lens

Introduction

The previous chapter identified gaps in the current understanding of autism, which may lead to misunderstandings and misaligned support. This chapter aims to provide a broader perspective by exploring the question, "What is autism?" through an alternative lens.

Some autism research has focused on specific cognitive and perceptual differences, such as those identified through the Embedded Figures Test (Happé & Frith, 2006). One example is the "aberrant precision" account of autism, proposed by Lawson, Rees, and Friston (2014), which explains autistic perception through predictive coding and Bayesian inference. This framework suggests that autistic perception arises from an imbalance in how sensory evidence is weighted relative to prior expectations.

Theories that emphasise cognition and perceptual differences have significantly enriched our understanding of autism, providing valuable insights into both neurocognitive mechanisms and practical support strategies. This chapter does not seek to challenge or diminish these contributions but rather to build upon decades of research, from the 1970s onward, by offering a broader, integrative perspective on autism.

This chapter adopts a complex systems approach (Galea, Riddle, & Kaplan, 2010; Kroelinger et al., 2014), which acknowledges that multiple interacting factors influence health and development over time. Additionally, it incorporates the eco-bio-developmental framework (Shonkoff et al., 2012), which integrates insights from various disciplines to examine factors that support or hinder developmental outcomes.

Two developmental theories of autism are proposed:

1. The Adapted Phenotype Theory (APT) — This theory explores the origins of autism, its evolutionary advantages, and the role of prenatal stress.
2. Autistic Development Theory (ADT) — This theory examines how modern societal and environmental factors shape autistic development and lived experiences.

While these theories could be merged, this chapter maintains them separately for clarity. Evolutionary science seeks to provide both proximate and ultimate explanations. Ultimate explanations are *why* something exists and proximate explanations are *how* it works. The Adapted Phenotype Theory offers an ultimate explanation (why autism exists), while the

Autistic Development Theory provides a proximate explanation (how autism manifests) (Scott-Phillips, Dickins, & West, 2011).

A concept referred to in this chapter is "optimal outcomes," this describes cases where individuals no longer meet diagnostic criteria for autism (Eigsti, Fein, & Larson, 2023). The diagnosis of autism is based on observable challenges that an individual displays. This chapter proposes that these symptoms are not the core life-long differences, but symptoms of stress, a mismatch between the person's needs and the environment and some may be developmental in nature. Given this, if a person has developed and uses strategies that lead the person to live without the challenges associated with the diagnostic criteria and fulfil their potential with the enhancements of the adapted phenotype.

Part One
Proposing An Evolutionary Perspective of Autism: The Adapted Phenotype Theory

Introduction

The previous chapter discussed the predominant historical and current autism theories. This chapter will move on to discuss genetic findings and prenatal maternal circumstances that have been found to lead to higher rates of autism. It will propose that the conditions and experiences that have been identified are likely to lead to maternal stress and that maternal stress may be the 'insult'[3] that triggers epigenetic adaptations in the foetus, subsequently changing the phenotype. This concept will be expanded by describing how these adaptations may benefit the infant and mother, in both infancy and adult life, through proposed changes in the superior colliculus (SC) and hypothalamic-pituitary-adrenal (HPA) axis. The adaptions will then be discussed in the context of the modern world and propose that modernity leads to the adaptions becoming maladaptive in certain circumstances. Finally, the chapter will explore the possibility of these adaptions being shared with other species and potentially are ancient adaptations to environmental pressures during foetal development.

Characteristically, most researchers approach autism as a maladaptive condition and seek to find a contributory deficit. In the face of growth in the diagnosis of autism and the widespread lack of resources to offer support, this thesis argues for a change in approach. Rather than considering autism as maladaptive, this section seeks to explore autism as an evolutionary adaptation. The insights offered may shift and shape the understanding of

[3] This term is a medical term used to refer to the cause of a physical or mental injury. These are typically regarded as either genetic or environmental.

autism and support of autistic people. Recent years have seen several conditions being understood through an evolutionary lens and it is proposed that this approach may inform understanding and support (Reser, 2011). Autism has previously been conceptualised as an evolutionary adaption by the Solitary Forager Hypothesis (Reser, 2011), the Social Motivation theory (Chevallier et al., 2012), Extreme Male Brain theory (Baron-Cohen, 2002), Extreme Imprinted Brain theory (Badcock & Crespi, 2006) Polyvagal theory (Stephen W. Porges, 2003), and Empathizing vs Systemising theory (Baron-Cohen, 2009). The theories discussed provide a good case for the potential for autism to be considered as an evolutionary adaptation, though none provide a comprehensive explanation. This chapter seeks to offer an alternative evolutionary perspective, and the following section describes the processes that are necessary when forming evolutionary explanations.

Evolutionary Psychology

When forming explanations for phenomena, evolutionary psychologists use adaptationist thinking, which emphasises the functionality of a trait or behaviour (Bjorklund & Pellegrini, 2000). Evolution is said to produce at least three outcomes; adaption, by-products and 'noise'. Noise refers to random effects, such as mutations, and by-products are characteristics that do not solve a recurring problem. Adaptions are reliably developing inherited characteristics that occur from natural selection and solve some problems of survival or reproduction in the environment (Bjorklund & Pellegrini, 2000).

Bjorklund and Pellegrini (2000) suggest that a developmental approach should be used to answer these questions by understanding the adaptive value of a behaviour at a *specific developmental time*. They explain that natural selection has functioned to adapt organisms to the current environment, and the environments and selective pressures experienced by our ancestors will be different early in development to those experienced later in life. A definition of The Environment of Evolutionary Adaptedness is *'the ancestral environment to which a species is adapted. It is the set of selection pressures that shaped an adaptation.'* (Bennett, 2018. p.1).

There are five principles that evolutionary psychologists should apply to topics. These are:

Principle 1 *- The brain is a physical system. It functions as a computer. Its circuits are designed to generate behaviour that is appropriate to your environmental circumstances* (Cosmides & Tooby, 2009. p.4).

Principle 2 *- Our neural circuits were designed by natural selection to solve problems that our ancestors faced during our species' evolutionary history* (Cosmides & Tooby, 2009. p.4).

Principle 3 *- Consciousness is just the tip of the iceberg; most of what goes on in your mind is hidden from you. As a result, your conscious experience can mislead you into thinking that our circuitry is simpler than it really is. Most problems that you experience as easy to solve as they are difficult to solve – they require very complicated neural circuitry (C*osmides & Tooby, 2009 p.6).

Principle 4 *- Different neural circuits are specialised for solving different adaptive problems* (Cosmides & Tooby, 2009. p.7).

Principle 5 *- Our modern skull houses a stone age mind* (Cosmides & Tooby, 2009 p.10).

The Variability Selection Hypothesis (VSH) offers a theory of human evolution (Potts, 2012; 2013). In VSH, variability stands for the history of environmental instability experienced by a population of organisms (Potts, 2012). The idea of variability selection is that when habitat variability is increased, heritable traits that enhance plasticity or adaptive versatility are preferential over traits that flourish in more stable environments. It is suggested that over time the lineage may improve adaptive versatility and become ever more able to adjust to environmental variability through physiological, behavioural and ecological plasticity (Potts, 2013).

Autism may be a manifestation of the adaptive plasticity described in VSH. If autism is an evolutionary adaptation, there should be strong genetic involvement and this is explored in the following section.

Genetic Involvement in Autism

Epigenetics refers to the heritable changes in gene expression that occur without changes to DNA (Bollati & Baccarelli, 2010). Intense World Theory (as discussed in chapter two) proposes that autism is a poly-genetic[4], epigenetic condition, triggered by an insult and the autistic 'pathology' unfolds during development (Markram & Markram, 2010 p. 3). Brain hypertrophy is triggered by an epigenetic insult that leads the brain to be excessively reactive to the environment (Markram & Markram, 2010).

The genetic causes of autism have been heavily researched, though, to-date, have not identified a single genetic factor (Lee et al., 2020). Genetic studies have identified over a thousand genes that contribute to the increased likelihood of autism (Wiśniowiecka-Kowalnik & Nowakowska, 2019) though there is insufficient evidence for autism-specific genes (Myers et al., 2020). An integrated approach that includes gene and environmental interactions has

[4] Poly-genetic means a number of genetic sources.

been advocated for, as this is thought to be more helpful than focusing solely on genes (Tordjman et al., 2014). Tordjman et al. (2014) suggest considering epigenetic remodelling by environmental factors would provide a greater opportunity to understand autism (Tordjman et al., 2014). It is proposed that if a disorder is polygenetic, it is likely that the genes that are involved lead to traits that are beneficial to the individual (Ploeger & Galis, 2011). The number of genes that have been identified leads to the prospect that autism may be an evolutionary adaptation. If applying the Tordjman et al. (2014) proposal, to combine genes and environmental interactions to further understanding of autism, the prenatal environmental factors that have led to higher rates of autism should be considered, and this is the focus of the next section.

Insults During Pregnancy Linked to Autism

Research has identified a link between exposure to stressful environmental weather events during pregnancy and autism prevalence (Kinney, Miller, Crowley, Huang, & Gerber, 2008). The most destructive storms between 1980 and 1995 in Louisiana were identified using National Weather Service data. The prevalence of autism increased significantly with the greater severity of the weather in the pre-natal storm. The increased prevalence was found in children exposed during the middle and later stages of pregnancy. These findings highlight that prenatal exposure to stressful environments may lead to increased autism.

A strength of this study is that utilizing hurricanes and tropical storms as natural experiments allowed the researchers to examine the effects of significant environmental stressors on prenatal development. This leads to a study being undertaken without ethical concerns associated with experimental manipulation. A further strength is the study identified a dose-response relationship, with autism prevalence increasing in line with the severity of prenatal storm exposure. This strengthens the argument for a potential causal link between prenatal stress and ASD. Findings indicated that exposure during specific gestational periods, particularly months 5-6 and 9-10, was associated with a higher risk of developing ASD. This insight contributes to understanding critical windows in prenatal development.

A limitation of the study is the reliance on aggregated data and the lack of specific information on individual maternal stress levels, coping mechanisms, and personal experiences during the storms. The research did not account for other environmental factors, such as exposure to toxins released during storms, which could also impact neurodevelopment. Additionally, variations in socioeconomic status and access to healthcare services across different regions might confound the results. The study utilised data from the state mental health system, which may not capture all ASD cases, particularly

those diagnosed and treated privately. This could lead to under-estimation of prevalence rates and affect the generalizability of the results.

In summary, while the study provides valuable insights into the potential impact of prenatal environmental stressors on autism prevalence, the limitations highlight the need for further research with more detailed individual-level data and consideration of additional confounding factors to establish a clearer causal relationship.

After the Quebec ice storm in 1998, a study of women who were pregnant during the storms found that autism traits and autism prevalence rates rose with exposure to increasingly severe stress (Walder et al., 2014). Eighty-nine women completed objective exposure and subjective distress questionnaires six months after the storm, followed up six months after their due date and when the children were six and a half years old. The Storm32 scale measured objective hardship under four categories of exposure: Threat, Loss, Scope and Change. Subjective distress was measured using the Impact of Event Scale-Revised, which provides scores for symptoms related to post-traumatic stress disorder; Intrusive Thoughts, Hyperarousal and Avoidance. Other maternal factors such as anxiety, major life events and depression were also assessed alongside child perinatal factors such as gestational age, foetal growth, and pregnancy/birth complications using the information in the child's vaccination booklet. The outcome measure was the Autism Spectrum Screening Questionnaire, a checklist assessing traits and symptoms, such as communication, social interaction, and restricted, repetitive behaviours, when the children were six and a half years old.

Maternal reported objective hardship and subjective distress were associated with more severe autism traits, and these strongly predicted autism traits in the children beyond all other predictors that they measured (Walder et al., 2014). In contrast to Kinney et al. (2008) who found *mid to late* pregnancy exposure was associated with an increased autism risk, this study found that *early* pregnancy exposure with high levels of maternal objective hardship to be associated with increased autism traits.

A strength of this study is that the study used a natural disaster as an unplanned stressor, allowing for the study without ethical concerns associated with experimental stress induction. Data on objective hardship and subjective distress were collected shortly after the ice storm, reducing recall bias and enhancing the accuracy of stress exposure assessment. The study differentiated between objective hardship, for example, days without electricity, and subjective distress, providing a nuanced understanding of how different stress dimensions affect child development. The research explored how the timing of stress

exposure during pregnancy influenced outcomes, identifying that early pregnancy exposure to high levels of objective hardship was associated with increased autism-like traits.

Limitations of the study are that the sample is small, comprising 89 children, which may limit the generalisability of the findings and the statistical power to detect smaller effects or interactions. Participants were from a specific geographic region (southern Quebec) and experienced the same natural disaster, potentially limiting the applicability of results to other populations or stressors. Autism-like traits were assessed using maternal reports via the Autism Spectrum Screening Questionnaire (ASSQ), which could introduce bias due to subjective perceptions or maternal mental health influencing reporting. The study assessed autism-like traits in a non-clinical sample, meaning the findings relate to subclinical variations rather than clinically diagnosed autism spectrum disorders. While the study controlled for certain factors, other unmeasured variables (e.g., genetic predispositions and postnatal environment) could influence the observed associations between post-natal maternal stress and autism-like traits.

In summary, the study provides valuable insights into the potential impact of prenatal maternal stress on the development of autism-like traits in children. However, the limitations suggest that further research with larger, more diverse samples and objective assessments is necessary to confirm and extend these findings.

Further to the Haiti earthquake in 2010, a study of 364 mother-child survivors used the Earthquake Experience questionnaire, the Peritraumatic Distress Inventory and the PTSD Checklist Specific to collect maternal data. Child data was reported by mothers completing the Autistic Behaviours Scale-Revised and the Child Behaviour Checklist. The study found that peritraumatic distress was significantly associated with maternal symptoms of PTSD, and these were associated with autism symptoms in the child at three years of age (Blanc, Rahill, Spruill, Jean-Louis, & Mouchenik, 2020).

The study used the 2010 Haiti earthquake as a natural experiment, allowing researchers to examine the effects of acute prenatal stress without ethical concerns associated with inducing stress, which is a strength of the design. By assessing maternal PTSD symptoms and child autistic behaviours three years post-disaster, the study minimized recall bias and provided temporal insights into the development of ASD challenges. The study employed standardised instruments, such as the PTSD Checklist-Specific (PCL-S) for maternal PTSD and the Child Behavior Checklist (CBCL) for child behaviours, enhancing the reliability of the findings. By evaluating maternal PTSD symptoms, the study acknowledged the potential mediating role of maternal mental health on child developmental outcomes.

The study's cross-sectional nature limits the ability to establish causality between prenatal earthquake exposure, maternal PTSD, and child ASD challenges. The absence of pre-earthquake data on maternal mental health and child development hinders comparisons and the ability to attribute observed outcomes solely to earthquake exposure. The study did not account for other variables, such as genetic predispositions, postnatal environment, or additional traumatic events between 2010 and 2013, which could influence the development of ASD challenges.

Moving from natural disasters to other potential stressors, a prospective study found that prenatal maternal stress was significantly associated with the child displaying autistic traits at two years old (Ronald, Pennell, & Whitehouse, 2011). This longitudinal study used the predictor variable of ten everyday major life stressors. These events were reported at 18- and 34-weeks' gestation and ensured that the same event was not recorded twice. The pervasive developmental problems scales were completed during the second year. Prenatal maternal stress was found to be associated with autistic traits in males only and not females (Ronald et al., 2011).

A strength of the study is that the longitudinal approach allowed for the collection of prenatal stress data during pregnancy, reducing recall bias. With data from a substantial cohort, the study had sufficient statistical power to detect associations between prenatal stress and neurodevelopmental outcomes. The analysis adjusted for various potential confounders, including socioeconomic status, maternal age, and smoking during pregnancy, strengthening the validity of the findings. Examining males and females separately, the study identified sex-specific associations, noting that prenatal stress predicted ADHD behaviours in both genders but autistic traits predominantly in males.

Limitations are that both prenatal stress and child behavioural outcomes were assessed via maternal questionnaires, which may introduce reporting bias or reflect maternal perceptions rather than objective measures. Additionally, it is worth noting that prenatal stress could be confounded with genetic links to autism. The study assessed ADHD and autistic traits using behavioural checklists without formal clinical evaluations, limiting the ability to confirm diagnoses. The cohort consisted primarily of individuals from Western Australia, which may limit the applicability of the findings to more diverse populations.

In summary, while the study provides valuable insights into the potential impact of prenatal maternal stress on the development of ADHD and autistic traits in early childhood, the limitations highlight the need for further research using objective measures, clinical assessments, and diverse populations to establish more robust conclusions.

Other prenatal risk factors have been associated with autism, including maternal age, gestational diabetes, gestational bleeding, multiple births, and immigration, especially when living in urban rather than rural areas (Tordjman et al., 2014). A more recent paper has identified parental age, foetal environments, pregnancy complications and medications, nutrition, toxins and psychosocial factors being related to increased rates of autism (Bölte, Girdler, & Marschik, 2018). Perinatal risk factors have also been reported as suboptimal perinatal conditions (Schieve et al., 2014).

The numerous factors that have been shown to influence an increased likelihood of autism may all involve the mother experiencing varying degrees of stress during the pregnancy consequential to these factors. Maternal prenatal stress has been associated with variations in foetal development, to which boys seem more vulnerable; these include foetal neurodevelopment which the authors propose may be relevant to future functioning (Walsh et al., 2019). A paper recognised that the gene x environment factors in the development of autism are beginning to be explored. The paper has identified that maternal prenatal stress and immune dysregulation are associated with autism. It is proposed that these conditions lead to microbiome and epigenetic changes in the foetus that the researchers suspect have downstream changes to neurotransmitter systems (Beversdorf, Stevens, & Jones, 2018).

The Potential Involvement of the Superior Colliculus in Autism

This section proposes that the brain region that may be involved in the enhanced sensory processing differences found in autistic individuals, is the Superior Colliculus (SC).

There are two complementary visual processing pathways in the brain (Jure, 2019). The ventral pathway is responsible for central, foveal retinal vision, representing 90% of visual input and enables slow, detailed, and colourful analysis of stimuli. The dorsal pathway is fast, mainly non-conscious, with low resolution and mainly receives stimuli from rods located in the peripheral visual field (Jure, 2019). The dorsal pathway inputs sensory stimuli to the superior colliculus (SC) and the Pulvinar. The role is multifocal and is *'pre-attentive and very sensitive to any movement or change in contrast luminescence'* (Jure, 2019, p. 1).

The SC is an ancient brain region and is reported to process sensory information very quickly and act as a hub to signal other brain regions (White & Munoz, 2012). The SC has been described as the *'Fast Detector-First Response'* (Soares, Maior, Isbell, Tomaz, & Nishijo, 2017, p.1), giving the ability to detect, assess and respond to danger and social stimuli.

The SC is divided into layers, superficial and deep. The superficial layers process visual stimuli from the peripheral visual field, receiving input from the retina and visual cortex (King, Hutchings, Moore, & Blakemore, 1988). The neurons project to the deep layers and

other brain areas, such as the Pulvinar (Lee, Tran, Turan, & Meister, 2020). The deep layers also receive stimuli from the auditory and tactile sensory modalities. Neurons in the motor layers play a role in attention, decision making and subsequent action (Basso & May, 2017). Pitti, et al. (2013) propose that the sensory alignment in the SC is important for supporting social skills at birth (facial preference and mimicry). It has been found that the SC and striatum are functionally mature in the third trimester of pregnancy to support the control of eye movements and facial behaviours. Neonates have been found to engage in social behaviours, and it has been argued that the visual cortex is not mature enough to support these early social skills (Pitti et al., 2013). A primate study found that SC neurons had a preferential response to face-like patterns, and there is evidence that the SC and pulvinar form the subcortical visual pathway for innate face detection (Le et al., 2020).

Jure (2019) highlighted that a common factor in cognitive theories of autism, is the atypical nonconscious visual attention, with a bias towards local processing in Weak Central Coherence theory (Happe & Frith, 2006) or stronger local processing in Enhanced Perceptual Functioning theory (Mottron et al., 2006). Jure (2019) proposes that the SC is the brain region that may be responsible for the differences in visual and sensory processing that we see in autism. Jure (2019) suggests that there is evidence that the SC is responsible for visual behaviour in the first months of life, processing visual tasks and providing a hub to integrate visual and non-visual information from internal and external sources and make non-conscious decisions where to focus attention and behavioural response. Jure (2019) describes the SC as a hub for developing brain networks that support social, emotional and communication behaviours, and in autistic individuals, there may be disruption in these functions.

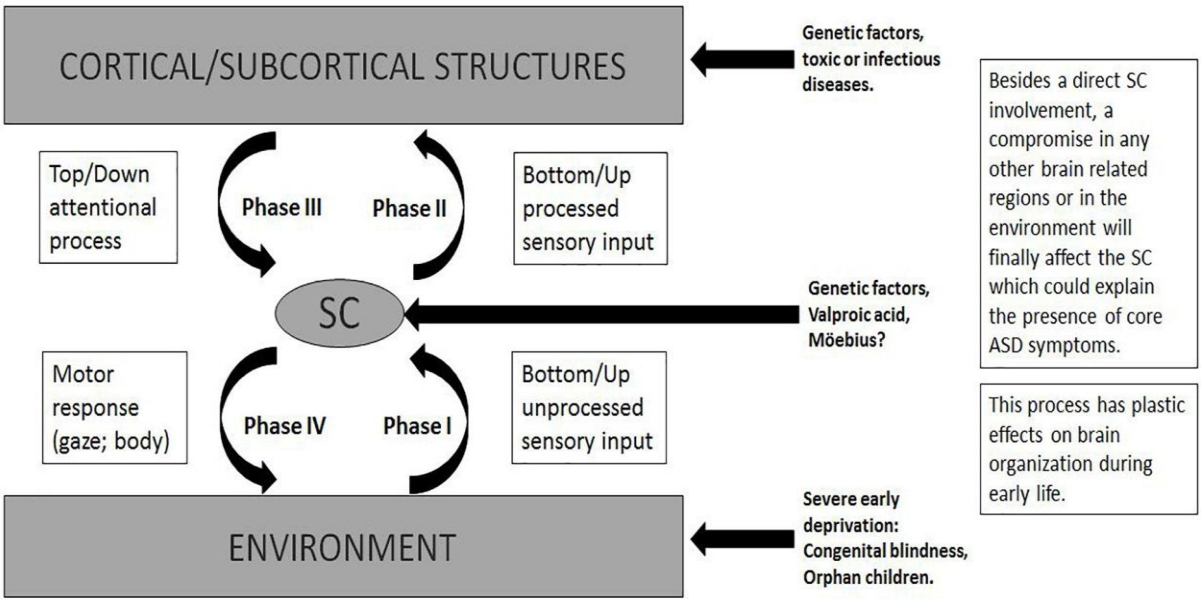
Rapid face processing is undertaken in the subcortical pathways, made up of the SC, the pulvinar nucleus of the thalamus and the amygdala (Hadjikhani et al., 2017). Studies have shown that when autistic individuals are constrained and forced to look into the eyes of faces expressing different emotions, there is abnormally high subcortical activation in comparison to controls (Hadjikhani et al., 2017), with higher pulvinar and amygdala activation. The pulvinar receives input from the SC, and the most significant difference between groups was found when autistic individuals were looking at fearful faces (Hadjikhani et al., 2017). These findings suggest that the SC is hyper-activating in response to visual stimuli in autistic individuals, especially stimuli representing threat or fear.

The SC has been reported to be a part of the defence response to threat and can generate a coordinated autonomic, respiratory and somatomotor response to sensory stimuli. Threats to survival are categorised into the sub-types of physical and psychological

stressors. Physical stressors directly threaten homeostasis, such as infection, while psychological are either actual or perceived threats. The psychological stressors can be reduced further to conditioned (based on previous experience) and unconditioned intrinsically threatening stressors (such as a predator sighting) that activate different neurons in the brain. Autonomic responses to these psychological stressors are also reported to be mediated by different pathways in the brain (Dampney, 2015).

There is evidence that the SC response to fear stimuli is essential for routing fear-relevant information (Almeida, Soares, & Castelo-Branco, 2015). The researchers suggest that the peripheral coarse processing the SC undertakes plays a role in the detection of phylogenetic[5] fear-relevant stimuli (Almeida et al., 2015).

Figure 2. The Superior Colliculus' Top-Down & Bottom-Up Attentional Process (Jure, 2019, p. 8)



There is a strong case for the involvement of the SC in autism. Jure's (2019) proposals are relatively recent and studies supporting the involvement of the SC have not yet been undertaken. Further to the development of APT, a study using fMRI has found significantly increased functional connectivity between the left SC and the right pulvinar (the largest nucleus of the thalamus) (Huang et al., 2022). This finding lends support to the involvement of the SC in autism. In support of the concept of the involvement of the SC in autism, the following section will discuss studies that have identified environmental pressures during development that have led to changes in the size and function of the SC or optic tectum (OT) in non-mammals.

[5] Phylogenetic – relating to the evolutionary development and diversification of a species or a particular feature of an organism

Environmental Pressure During Foetal Development & Potential Enhancement of the Superior Colliculus / Optic Tectum

The human brain is extremely complex and the case has been made for the use of animal studies to understand the brain to expand understanding of brain disorders (Buffalo, Movshon, & Wurtz, 2019). The Zebra fish has been identified as the ideal species to use for behavioural neuroscience, developmental biology and genetics studies. It is argued that it is a complex vertebrate, easy to breed and cost-effective (Gerlai, 2011). For these reasons, there is a plethora of neuroscience research that uses fish and rodents to garner insight into human neurology. The following section will consider the evidence that environmental factors influence brain development in a variety of species.

A study into the effect of a predator's biomass on the size of the brain and brain regions was undertaken with wild guppies from 15 different areas with varying predation pressures. The study found that the optic tectum[6] of guppies was significantly increased in size when the biomass of the predator was larger (Kotrschal & Kolm, 2017). These findings suggest that in response to more significant environmental pressure, the Optic Tectum increases in size, potentially enhancing threat detection and survival.

It has been proposed that an enhanced understanding of human neural disorders may occur if a combination of species is studied (Manger et al., 2008), the following study was focused on rats. Valproic acid (VPA), a drug used to treat epilepsy, has been linked to autism when there has been prenatal exposure (Markram & Markram, 2010). Rats exposed to VPA prenatally are found to be hyper-reactive, hyper-connective and display hyper-plasticity and learning. Several experiments were undertaken on *Xenopus laevis* (African clawed frog) tadpoles exposed to VPA and controls who were raised in a standard medium (James et al., 2015). Tadpoles were in groups exposed to VPA at developmental stage 47 or 49, and each experiment used tadpoles from different husbandry. The behaviours that were subsequently assessed were acoustic startle, schooling, seizure[7] and collision avoidance. The collision avoidance experiments provided environments where two types of avoidance, fast or slow, would be appropriate. When fast escape occurred in the VPA tadpoles, they performed less effectively than controls; however, with the slow condition, the VPA tadpoles escaped with a very different response to controls and escaped with speeds more likened to a fast escape response. There were also interesting insights regarding the startle response. There were no differences in response for the initial startle; however, the control tadpoles demonstrated short and long-term habituation to the startle stimuli, and the VPA tadpoles did not habituate. There were also different schooling behaviours; the control tadpoles, either

[6] The optic tectum is the region called the Superior Colliculus in mammals.
[7] Tadpoles that were used in these experiments were not used in further experiments.

schooled closely or swam around the bowl in small groups, while the VPA tadpoles distributed evenly across the bowl. These behavioural changes indicate a phenotype that is more responsive to threatening stimuli and is less group-dependent. The study also found the OT of the tadpoles was hyper-connected (James et al., 2015) as was the case in the Markram and Markram studies (2010).

Studies that have focused on VPA and rats have found that prenatal exposure leads to behavioural abnormalities, sensory processing differences and anatomical changes to the Superior Colliculus (SC). The changes were found in rats who were exposed to a single dose of 400 or 500 mg/kg, and rats exposed to multiple doses of 200 mg/kg did not share the same manifestations, leading the researchers to conclude that changes appear dose-dependent (Dendrinos, Hemelt, & Keller, 2011).

Other environmental conditions have been shown to alter the OT; *Hemichromis bimaculatus* (Jewel fish) developing in crowded and non-crowded conditions show different neuronal patterns in the OT, and the authors of the cited article propose:

> *'Our manipulations have apparently resulted in the emergence of 2 neuronal patterns characterizing crowded and noncrowded individuals; thus, we cannot rule out the possibility that this neuronal system may possess more than one potential developmental end-point which is determined by the environmental conditions at early ages.'* (Wesley & Coss, 1982, p. 467).

The authors propose that there may be more than one potential development trajectory in this species that is influenced by environmental factors, and appears centred on the developing OT. This adaptation to environmental pressure makes sense, as a crucial feature for survival is the ability of the brain to alter neural circuits that support flexible development and adaptations in response to environmental variability (Richards, Aizenman, & Akerman, 2010).

Similarly, *Pungitius pungitius* (sticklebacks) show variations in brain size, and regions of the Telencephalon, OT, Cerebellum and Hypothalamus are involved (Gonda, Herczeg, & Merilä, 2011). The variations were found in different environments that would have exerted varying degrees of environmental pressure, with the researchers suggesting either a local adaption or an environmentally induced variation (Gonda et al., 2011).

These studies highlight that environmental pressure or instability in early developmental stages can lead to changes in the OT/SC in several species. The adaptations appear to enable the phenotype to be hyper-responsive to threat and fear-inducing stimuli, potentially enhancing chances of survival and reproduction.

As has been previously discussed, there is a link between environmental instability / maternal stress and autism prevalence. This thesis has proposed that environmental pressure during foetal development results in a hyper-responsive SC in predisposed infants. These infants are likely to show less reliance on others, display hyper-fear, be hyper-responsive to threat and show hyper-plasticity and learning, as has been found in other species (Markram & Markram, 2010). These phenotypic traits may be an enhanced threat detection ability for environments where there may be greater pressures on survival.

A strength is that the studies cited draw on a variety of species, including guppies, rats, Xenopus tadpoles, zebrafish, jewel fish, and sticklebacks. This cross-species approach strengthens the argument that environmental factors may influence brain development across different vertebrates. The comparison between species allows for broader generalizations about the potential mechanisms influencing brain development, particularly the Optic Tectum (OT) and Superior Colliculus (SC). Several independent studies have found similar results regarding the effects of environmental pressure on brain development, particularly the OT/SC. The consistency in findings across different methodologies and species adds credibility to the idea that environmental pressures shape neural structures.

The studies on prenatal exposure to Valproic Acid (VPA) in rats and Xenopus tadpoles show dose-dependent effects, which suggests a causal relationship rather than mere correlation. The controlled nature of these experiments (e.g., varying doses of VPA, predator biomass comparisons) allows for a more precise understanding of how environmental factors alter neural development. Studies on wild guppies and sticklebacks examine natural environments with varying degrees of predation pressure, providing real-world context.

While animal models provide useful insights, more direct human research is needed to confirm these hypotheses. Some of the studies cited focus on immediate or short-term neural and behavioural changes but do not track long-term developmental outcomes.

The evidence presented in this section supports the idea that environmental pressures can shape neural development across multiple species, particularly affecting the OT/SC. However, there are limitations, particularly regarding the extent to which these findings can be generalised to humans. Further human research is needed to confirm the proposed links between prenatal environmental stress and autism-related traits.

Environmental Pressure Leading to Enhanced HPA Reactivity

In this section, the evidence that the hypothalamic-pituitary-adrenal (HPA) axis is elevated in autistic people is considered. Insights from animal studies are explored regarding prenatal programming of the HPA axis in response to prenatal maternal conditions, and it is proposed

that this may be an ancient evolutionary adaptation to adverse conditions. The HPA axis is a much-researched psycho-neuro-endocrine system. Glucocorticoid hormones, cortisol and corticosterone, are the effector hormones that provide signals to cells and systems to enhance performance concerning environmental, physiological and circadian demands. Activation of the HPA axis ensures that the brain responds appropriately to a stressor. Dysregulation in the HPA axis is associated with a wide range of disorders (Spencer & Deak, 2017). Prenatal stress and maternal immune dysregulation have previously been associated with autism (Beversdorf et al., 2018), and studies have found that the HPA axis is dysregulated in autistic children (Courtemanche, Black, & Meyer, 2021; Spratt et al., 2012)

One study found significantly elevated peak cortisol levels and prolonged recovery periods in autistic children in response to a stressor compared to controls. The authors of the study suggest that the findings show an increased reactivity to stress and novel stimuli in autistic children (Spratt et al., 2012). Similar results were found in a further study which led researchers to propose that the data shows the likelihood of very high levels of chronic HPA axis arousal and anxiety in autistic children (Bitsika, Sharpley, Sweeney, & McFarlane, 2014). Children exposed to maternal stress or psychopathology in utero have been shown to have higher cortisone levels[8] in their hair at six years of age. Greater symptoms of psychopathology were also associated with increased cortisol in children. Where maternal stress was chronic, child cortisone levels were also higher, indicating that maternal stress's longevity may influence the HPA axis in offspring. While results were not significant for cortisone, the trend was similar to cortisol (Molenaar et al., 2019). These findings suggest that foetal exposure to stress and psychopathology alters the HPA axis of the foetus.

There is enhanced synaptic plasticity during the perinatal period and the brain is proposed to be sensitive to modulating external factors, such as stress. Early life stress (ELS) exposure has been found to induce adaptations to the HPA axis and the amygdala, hippocampus and prefrontal cortex (Van Bodegom, Homberg, & Marloes, 2017). It is proposed that the adaptions induced by ELS are to prepare the organism for similar adversities during adult life[9], imprinting an organism's neuroendocrine, neural and behavioural response to stress. The hyper-responsive HPA axis boosts the amygdala's excitatory drive whilst impairing the regulatory feedback of the hippocampus and prefrontal cortex. A mismatch occurs when the adversities are not present and can leave a vulnerability to psychopathology. Therefore, the adaptations are either advantageous or disadvantageous

[8] Cortisone is a biomarker for psychopathology and stress.
[9] The concept of programming is to explain the relationship between environmental events and stable alterations in phenotype (Meaney et al., 2007).

depending on the context (Van Bodegom et al., 2017). Development of the HPA axis begins prenatally, and some mechanisms protect the developing brain. Protection from exposure prenatally through the placental 11 β-hydroxysteroid dehydrogenase type 2 (11βHSD2) deactivates corticoid glucocorticoids (Van Bodegom et al., 2017). However, some do get through to the foetus, exposing the foetus directly and indirectly by inducing foetal HPA axis activation. Chronic maternal stress reduces 11βHSD2 activity, furthering foetal exposure, and if levels become high enough, it can induce changes in foetal programming (Van Bodegom et al., 2017).

In support of the involvement of impairment of the regulatory feedback of the prefrontal cortex in autistic people, brain imaging has shown that there is a reduction in connectivity from the median prefrontal cortex to the amygdala in autistic children (Li et al., 2021). Other studies have reported atypical hippocampal functioning in autistic adults (Ring, Derwent, Gaigg, & Bowler, 2017), supporting the proposal of impaired regulatory feedback in autism.

Prenatal programming has been linked to interactions between maternal hormones, the placenta, and the developing foetus, with compounding factors of foetal sex and stage of development adding to the complexity of these interactions (Howerton & Bale, 2012). Glucocorticoids pass through easily within the placenta; however, enzyme 11βHSD2 is present in high levels and can convert glucocorticoids to an inactive metabolite, thus protecting the developing foetus from high hormone levels. Glucocorticoids are necessary for the development of the foetal brain; therefore, maintaining the homeostasis of glucocorticoids is essential for the development of the foetal brain. Reduced activity of 11βHSD2, leading to increased foetal exposure to glucocorticoids, has been shown to cause complications with the birth and induce foetal programming for adult hypertension and hyperglycaemia. 11βHSD2 activities and sensitivities to maternal stimuli appear sex-specific.

In females, the enzyme is reduced in response to inflammation due to asthma or ethanol, whereas in males, activity increases with these maternal conditions (Howerton, & Bale, 2012). The authors suggest that sex-specificity may be one mechanism that leads to the sex biases found in neurodevelopmental programming (Howerton & Bale, 2012). It is widely reported that fewer females are diagnosed with autism than males, with population-based studies showing a ratio of three males to each female (Russell et al., 2021). There are proposals that this may be explained by females ‘masking’ their symptoms or behavioural characteristics presenting differently in males and females (Russell et al., 2021). Another factor of the sex-specific differences in the prevalence and presentation of autism may be due to the prenatal programme and this warrants further consideration.

Findings have also demonstrated that maternal stress causes placental inflammation, specifically with male foetuses, and this is likely the contributor to the sex-specific effects on the neurobehavioural outcomes for offspring. The findings were that early prenatal stress increased levels of immune response genes, including proinflammatory cytokines and chemokines in male placentas. The researchers also identified inflammation as a contributor to the sex-specific effects of maternal stress on foetal neurodevelopment (Bronson & Bale, 2014).

Sexual dimorphism was the focus of a more recent study that provided enlightening results of foetal sex modifying the gene expression in the placenta in response to metabolic and inflammatory stress (Barke et al., 2019). In response to acute exposure to immune activation, metabolic stress, or both conditions, sex differences influenced placental gene expression in mice (Barke et al., 2019). The study found that placental sex influenced gene expression in control mice, with 13 genes being significantly differentially expressed, eleven more highly expressed in males, and two more highly expressed in females. When placed under metabolic stress, males exhibited more changes in placental gene expression, while the condition of immune activation stress induced more placental gene changes in females. Interestingly, when both conditions were experienced, 74 out of 93 genes were similarly impacted in male and female placental tissue. Additionally, 21 genes changed in males and 28 in females, and genes were modulated up and down in all results (Barke et al., 2019).

An analysis of 114 results from 39 animal and human studies found an effect of prenatal stress on glucocorticoids in the offspring with a trend toward elevated levels, with extended post-stress exposure recovery showing the most significant effects. Glucocorticoid recovery was found to be longer (Thayer, Wilson, Kim, & Jaeggi, 2018), as has been found in autistic children (Spratt et al., 2012). A potential explanation was given as the maladaptive impact of allostatic load, with chronic stress exposure leading to a prolonged response with either delay or ineffective return to baseline levels (Thayer et al., 2018). The study also found little variation across species or life histories and no significant differences between mammals and non-mammals. The authors of the study propose that the findings are consistent with an ancient vertebrate origin of HPA axis programming (Thayer et al., 2018). This prospect is considered later in this chapter.

The findings discussed above highlight the influence that maternal conditions and experiences have on the developing foetus. More research needs to be done to understand the factors involved in prenatal programming and the possible relationship to autism, especially those related to the type and timing of insult and sex-specificity. However, the studies show conflicting results, though these may be due to an insult that induces maternal

stress and gestational timing. Another factor could be that while these distinct species potentially share the same evolutionary adaption, it is potentially ancient and these distinct species would have experienced their separate evolutionary pathways that may alter the outcome.

Most studies using rodents use maternal restraint as the stressor, and it is proposed that the adaptions prepare the organism for similar adversities in adult life (Van Bodegom et al., 2017). More insight may be gained by exposing rodents to stressors that have been identified as causing maternal stress associated with autism, such as environmental pressures. Nevertheless, it is possible that maternal stress may alter the placenta and phenotype of the foetus, leading to an altered HPA axis in autistic individuals. As is the case in the previous section, there is evidence that the altered HPA axis due to exposure to maternal stress in utero is shared with other species.

Multiple studies (e.g., Spratt et al., 2012; Bitsika et al., 2014) provide strong evidence that autistic children show increased cortisol reactivity and prolonged stress recovery times, reinforcing the idea that HPA axis dysregulation is a core feature of autism. The use of multiple human studies strengthens external validity, demonstrating consistency in findings across different samples. The studies incorporating rodents (Van Bodegom et al., 2017), primates, and other vertebrates (Thayer et al., 2018) indicate that HPA axis programming in response to prenatal stress is an ancient evolutionary adaptation. The similarity in findings across diverse species supports the hypothesis that prenatal programming may have a deep-rooted biological function.

Research on placental enzyme 11βHSD2 (Howerton & Bale, 2012; Wieczorek et al., 2019) provides a mechanistic explanation for how maternal stress may influence foetal HPA axis regulation. The combination of human neuroimaging studies (Li et al., 2021; Ring et al., 2017) with animal research provides a comprehensive view of how prenatal stress may shape neural structures involved in stress regulation (e.g., amygdala, prefrontal cortex, hippocampus). The use of rodents and other species enables controlled experimental manipulations that would be unethical in human studies, allowing for more precise investigations of causality.

While animal models provide valuable insights, they may not fully capture the complexities of autism in humans. Most studies use maternal restraint stress or pharmacological interventions (e.g., glucocorticoid exposure) in animals, which may not fully reflect real-world stressors that contribute to autism in humans. Some studies show conflicting results, particularly regarding the timing and type of prenatal stress exposure. For example, Molenaar et al. (2019) found higher cortisol levels in children exposed to maternal

stress, but statistical significance was not reached for cortisone. Differences in methodologies across studies—such as variations in stress exposure (acute vs. chronic), differences in species used, and discrepancies in cortisol measurement techniques—make direct comparisons challenging. While studies suggest that sex differences in placental adaptation may contribute to autism prevalence, the mechanisms remain speculative. Some findings indicate that males may be more vulnerable to prenatal stress due to reduced placental protection (Howerton & Bale, 2012; Bronson & Bale, 2014), but further research is needed to confirm whether these differences directly translate to autism risk.

Conclusion

Overall, the studies discussed provide some evidence (though largely correlational rather than causal) that prenatal stress and HPA axis dysregulation are associated with autism. The cross-species consistency supports the idea that these adaptations have deep evolutionary roots. However, limitations such as differences in animal models, methodological variability, and the need for more human longitudinal research indicate that more work is needed to fully understand the mechanisms involved. It is therefore tentatively proposed that the HPA axis modifications that have been identified in autism may be evolutionary adaptations in response to prenatal maternal stress. The epigenetic modifications result in a phenotype that is hyper-responsive to threat stimuli via enhancement of the SC and hyper-responsive to threats due to the adapted HPA axis. Further to this, animal studies have found that species that show these adaptions display other traits.

Hyper-plasticity, Developmental Stasis & Phenotypic Switching

The SC has been found to show high plasticity in both the short and long term in animal studies (Yu, Stein, & Rowland, 2009). A study of *Xenopus laevis* (African Clawed frog) tadpoles has found that restricting nutrients from the second week of life results in a developmental stasis. The tadpoles continue to swim and behave normally but do not progress through developmental stages, and neural progenitors almost cease cell proliferation. When food is reintroduced, neural progenitor cell proliferation is ten times more than typically developing tadpoles, and cell rates recovered to those of the fed control tadpoles. The elevated cell proliferation continued beyond catching up with fed tadpoles, persisting to the end of the experiment. These findings highlight the potential for a reversible developmental stasis in the OT (Mckeown, Thompson, & Cline, 2017).

The hyper-plasticity of the SC has been highlighted in another study that found the behavioural effects (reduced social play) of rats exposed to prenatal stress reversed. Prenatally stressed rats displayed impaired social play, disturbances in circadian rhythms,

and increased anxiety and HPA axis reactivity. When rats were provided with an enriched environment, the manifestations of prenatal stress decreased, social behaviours increased, and HPA axis reactivity reduced (Morley-Fletcher, Rea, Maccari, & Laviola, 2003).

The concept of developmental stasis may help further our understanding of the heterogeneity of autism. Autistic children experiencing language delays (pre-verbal) are also found to experience delays in motor functioning (fine and gross), exploration, and visuospatial cognition (Talkar et al., 2025). This is thought to be due to the complex interactions between the developmental domains and it is suggested that cognition should be considered as emerging from multiple interacting systems, grounded in bodily interactions with the environment (Hellendoorn et al., 2015). This leads to the proposal that pre-verbal autistic individuals may be experiencing a reversible developmental stasis. A framework of eleven distinct phases of cognitive developmental stages and phases of social-emotional development has been offered (Lewis & Granic, 2010). These stages and phases create a timeline of development from birth to five years. The social situations inducing emotions and the cognitive capabilities children possess to deal with them, change in each stage and phase (Lewis & Granic, 2010). Phase Six of the social-emotional development is the elaborated (sensorimotor) stage with the motor practice period that typically occurs between 12-16 months. This period is characterised by walking, and when infants are particularly interested in *'reversible operations'* (Lewis & Granic, 2010, p. 197) such as switching lights on and off, toys in a box and then out of the box. With reversible operations, they can streamline and systemise the bifocal co-ordinations that are the building blocks of this period. The social-emotional element of this period brings the first use of single words, and this new capacity to express oneself is thought to consolidate the sense of a shared world. I propose that these typical developmental behaviours can be observed in autistic individuals who are not yet using words, or who use few words, and the reversible operations activities undertaken are possibly being described as repetitive behaviours. There is a possibility that this developmental period may be in stasis preventing completion, syncing and movement onto the next phase of a non-time-dependent developmental window in some minimally verbal autistic people. Should this be the case, an appropriate setting with minimised sensory stimuli and provision of *developmentally* appropriate activities, may support individuals in this development stage to complete it and move on to the next stage.

Further explanation of the heterogeneity of autism may be found in the evidence of other species experiencing phenotypic switching, and modifying phenotypes. The environmentally triggered changes in gene expression resulting in a modified phenotype, have been the subject of debate. The concept of developmental phenotypic plasticity and subsequent phenotypic switching has been found in plants and animals (Burggren, 2020).

Burggren (2020) proposes that Gene X Environment's formula is too simplistic, and the formula should include both intergenerational and intragenerational epigenetics and development. He proposes the formula: (Genes x Environment) x Development, and adds an epigenetic component (Epi) to represent intragenerational and intergenerational environmental experiences resulting in modified gene expression, creating a within-life altered gene expression and ancestry. Further to this, Burggren (2020) proposes that the influence of stochasticity[10] should be represented and proposes Gene x (Environment + Epi) x (Development x Stochasticity). These factors interact and may lead to modified phenotypes resulting from developmental plasticity (Burggren, 2020). There are critical windows of development when an environmental stressor may lead to phenotypic switching, but the ongoing development time leaves an opportunity for additional switching.

The prevailing paradigm is that phenotypic modifications are irreversible. In contrast to this, a nuanced view of adult phenotypes is offered by Burggen (2020), with traits being considered non-plastic, irreversibly plastic and reversibly plastic. Factors such as the cost of plasticity, environmental variability and predictability, development rates and characteristics, are considered. It has been proposed that reversible developmental phenotypic switching (RDPS) can occur as an important mechanism for surviving climate adversity and evidence supporting this concept emerges from various species, including humans (Burggren, 2020).

To quote Burggren directly:

> *'In the most common pattern of reversible phenotypic switching, a developing organism takes a novel developmental trajectory in response to an environmental stressor, producing a modified phenotype which may be either advantageous or deleterious. Then, when the stressor inducing this modified phenotype disappears, the organism takes a second novel developmental trajectory returning it to the pathway leading to the normal range of adult phenotypes that may well be more appropriate for the typical environmental condition.'* (Burggren, 2020, p6)

The concept of RDPS may, in part, help further our understanding of the heterogeneity of autism. Phenotypic switching may explain the phenomena of optimal outcomes where children no longer meet the criteria for autism (Fitch, Fein, & Eigsti, 2015). Support for this concept are the findings of a study that focused on the local processing cognitive style displayed by autistic children. The study found that "high-functioning autistic children" (the authors' term) focused on local details when describing a picture, while optimal outcome children focus was the same as their peers. The researchers also reported that there was no residual weak central coherence in optimal outcome children (Fitch et al., 2015). This phenomenon may be explained by the concept of phenotypic switching.

[10] Stochasticity: lacking predictable order or plan.

The studies discussed in this section suggest that there is potential to alleviate the impact of some of the proposed phenotypic modifications that may be harmful to the individual throughout life, such as the proposed enhanced HPA axis. There is a great deal of opportunity to decrease the activation of the HPA axis by minimising environmental insults and supporting the use of strategies that are non-invasive, such as breathing techniques, frequency-reducing earplugs and tinted lenses (Ring, 2025).

This section has considered the evidence in other species of hyper-plasticity, developmental stasis and phenotypic switching that have been found in other species and is proposed to be an evolutionary adaptation. The shared nature of the adaptions is indicative that the enhanced SC and HPA axis are potentially ancient, and this is the focus of the following section.

The Potential Timescale of HPA Axis and Superior Colliculus Adaptation

It has been proposed that studies of biodiversity, development and disease should consider evolutionary information on species divergence (Kumar, Stecher, Suleski, & Hedges, 2017). It is possible to estimate a timescale of an adaptation by taking two present-day species that share an adaptation and calculating the node time (divergence) of their last known common ancestor ("TimeTree : The Timescale of Life", n.d.).

The Timetree timeline visualizes the divergence times of species with earth events and environmental history. Table 3 shows the species identified as experiencing altered glucocorticoid levels after exposure to prenatal stress, along with their estimated pairwise divergence times (EPDT) from Homo sapiens.

Table 2. Estimated Pairwise Divergence Times of Species, With Altered HPA Axis After Prenatal Stress Exposure, with Homo sapiens

Species	Common Name	Estimated Pairwise Divergence Time With Homo sapiens, Years in Millions
Danio rerio	Zebra fish (Du, Chen, Shi, Bian, & Zhao, 2020)	433
Thamnophis elegans	Western terrestrial garter snake*	312
Coturnix japonica	Japanese quail*	312
Gallus gallus	Red junglefowl*	312
Alopes lagopus	Artic fox*	96
Arctocephalus gazella	Antarctic fur seal*	96
Sus scrofa	Wild boar*	96
Ovis aries	Sheep*	96
Cavia porcellus	Guinea pig*	90
Rattus norvegicus	Brown rat*	90
Mus musculus	House mouse*	90
Pan troglodytes	Chimpanzee*	6.7

Species	Common Name	Estimated Pairwise Divergence Time With Homo sapiens, Years in Millions
Macca mulatta	Rhesus macaque*	Unable to Calculate
Lepus americanus	Snowshoe hare*	Unable to Calculate

Key: *(Thayer et al., 2018)

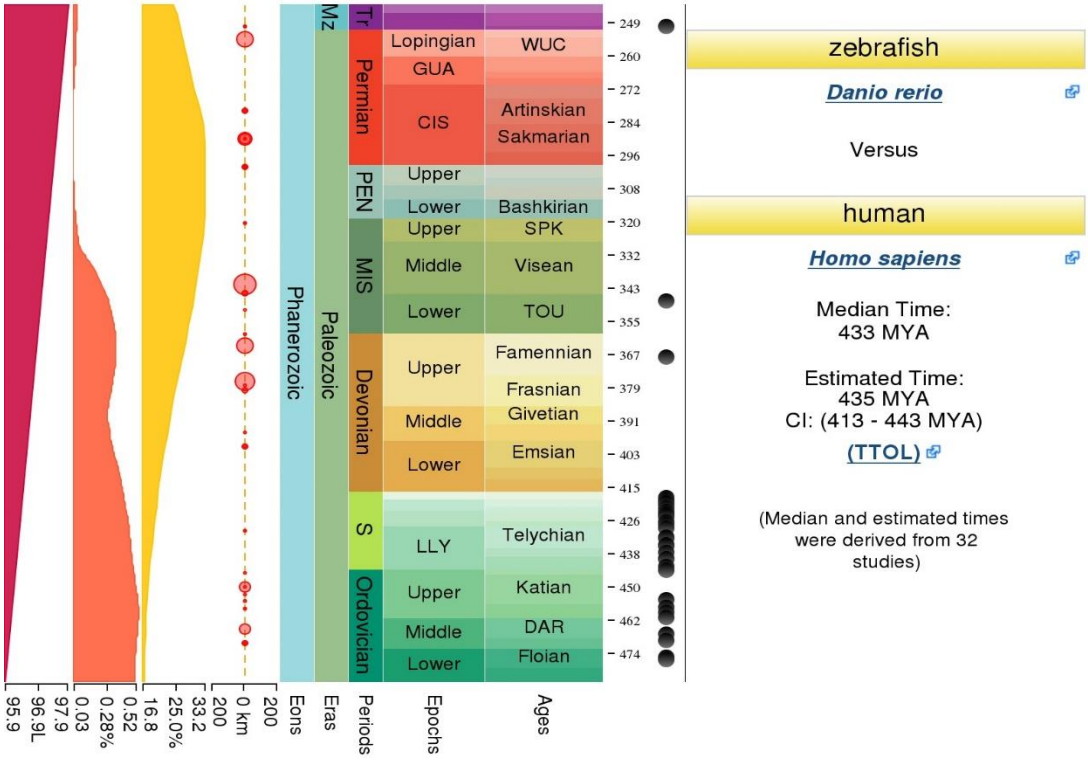
As Table 3. shows, the earliest pairwise divergence was four hundred and thirty-three million years ago, and this means that the altered HPA axis in response to prenatal stress may have occurred before the two species' last common ancestors divergence. The results of the calculation of one of the species, the *Danio rerio* (Zebra fish), are shown in Figure 4.

The same calculations have been made with the species sharing alterations to the OT / SC after exposure to prenatal stress, and the results are presented in Table 4. The results of the *Hemichromis bimaculatus (*Jewel fish) calculation are shown in Figure 5.

Table 3. Estimated Pairwise Divergence Times of Species, With Altered OT/SC After Prenatal Stress Exposure, with Homo sapiens

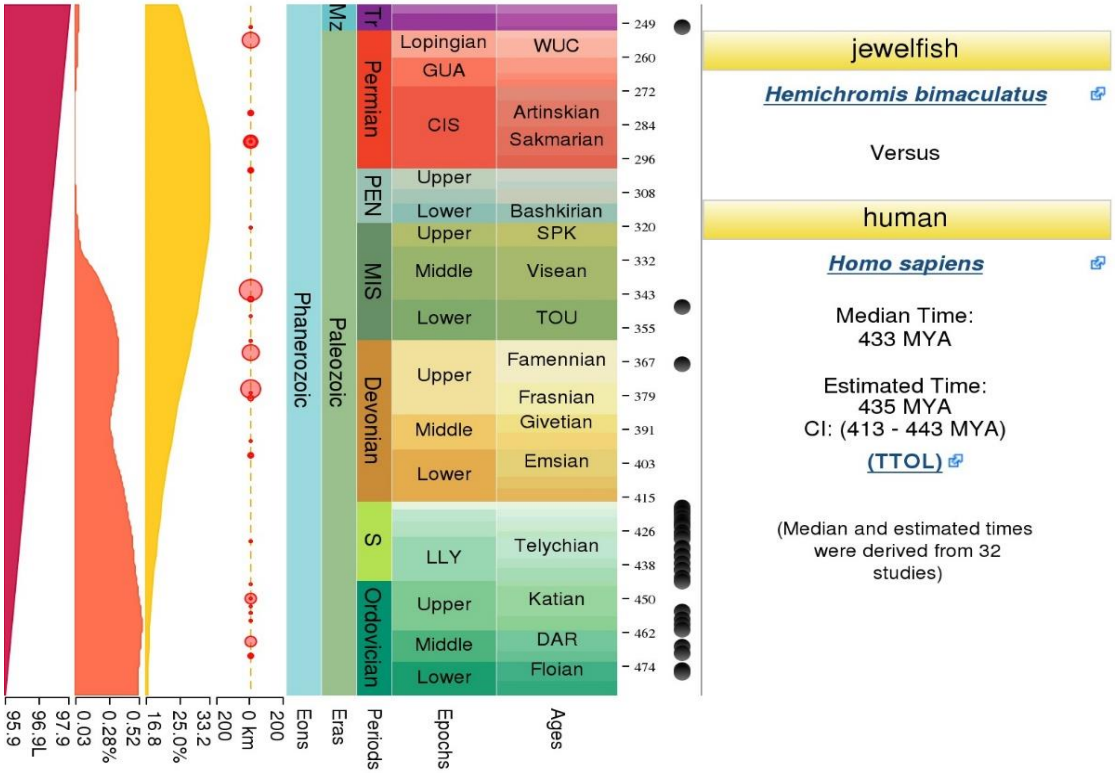
Species	**Common Name**	**Estimated Pairwise Divergence Time With Homo sapiens, Years in Millions**
Hemichromis bimaculatus	Jewel fish (Wesley & Coss, 1982)	435
Pungitius pungitus	Ninespine stickleback (Gonda et al., 2011)	435
Poecilia reticulata	Guppy (Kotrschal & Kolm, 2017)	435
Rattus norvegicus	Brown rat (Markram & Markram, 2010)	90

Figure 3. Pairwise Divergence Time for Danio rerio and Homo sapiens



("TimeTree :: The Timescale of Life," n.d.)

Figure 4. Pairwise Divergence for Hemichromis bimaculatus and Homo sapiens



("TimeTree: The Timescale of Life," n.d.)

Figures 4 and 5 show the divergence of the last common ancestor for species showing an altered HPA axis and altered OT/SC. The last known common ancestor divergence is estimated to be approximately four hundred and thirty-five million years ago for both calculations. Therefore, there is potential that the enhanced HPA axis and OT/SC are very ancient adaptations that have been conserved in several species for millennia. The persistence over millions of years, which continues to be shared by multiple vertebrates over a wide range of taxa, highlights the value of the enhanced threat detect and react adaptions in times of environmental instability.

Four hundred and thirty-five million years ago was the Ordovician period, which is known for the earliest biodiversification and extinction events that have been linked to physical changes in the environment. Two extinction events eliminated eighty-five per cent of species. It is thought that glaciation caused two environmental changes. The first was the cooling global climate and the second was the sea level decline, draining seas and later rising (Sheehan, 2001). Others, however, report that the events were caused by volcanism, warming and lack of oxygen (Mitchell & Melchin, 2020). Nevertheless, the catastrophic environmental events may have led to adaptations in some of the surviving species. It is

possible that the last common ancestors' survival during these extinction events was enabled by the enhanced ability to detect and respond to threats by adaptations in the OT/SC and HPA axis. For an ancient adaption to persist there needs to be continued advantages in later species, the advantages to our early ancestors are discussed in the following section.

Autism Advantages in Infancy in Times of Adversity

Evolutionary psychologists use adaptationist thinking, which highlights the functionality of a trait or behaviour (Bjorklund & Pellegrini, 2000). If autism is to be considered an evolutionary adaptation, there is a need to consider autism and its associated traits in relation to the environment of our early ancestors. The Pleistocene period, between 2.58 million years ago and 11,700 years ago, saw the emergence of the Hominin species. Of these early humans, Homo erectus appeared approximately 2 million years ago and was an early hunter/gatherer (Ono & Pawlik, 2020).

Natural selection favoured good problem-solving, as those who were good at problem-solving would have produced more children. Natural selection is slow, and it is said there has not been enough time for brain circuitry to become well-adapted to post-industrial life (Cosmides & Tooby, 2009). Therefore, modern humans are likely to continue to experience evolutionary adaptations that enhanced our ancestors' survival.

Critically important to our ancestors' survival would be the ability to deal with environmental variability. From an evolutionary perspective, adverse environmental conditions would require the mother to spend time dealing with the environmental problems and obtaining resources. It is proposed that the autistic infants' hyperfunctioning SC (Jure, 2019) leads to an enhanced visual system and it has been found that autistic infants have less reliance on the mother than non-autistic infants (Amso, 2016). These factors lead to the first possible advantage; autism frees the mother from some care responsibilities providing more time to deal with the issues arising from adverse environmental conditions, and enhancing the possibility of survival of both mother and infant.

The hyper-functionality of the SC may enable the infant to detect a threat quickly; the enhanced HPA axis enables the infant to respond and escape the threat rapidly. This ability, alongside hyper-fear and learning (Markram & Markram, 2010), helps the child learn about and respond to danger, keeping the child safe from harm and enhancing chances of survival. Another advantage of the potentially enhanced SC has been highlighted by the James et al. (2015) study that found tadpoles exposed to VPA did not habituate to harmless threats as the non-VPA tadpoles did. This lack of habituation to threat would ensure that any potential

threat from the environment was attended to and this would likely aid survival when there is environmental variability.

The hyper-functionality of the SC would also enable the developing child to be highly effective at hunting and gathering resources for nourishment, again, a trait highly advantageous for survival during environmental variability.

Enhanced sensory perception, hyper-plasticity and the hyper-learning brain (Markram & Markram, 2010) would enable the child to develop when resource availability allowed, *irrespective* of the child's chronological age. The SC is responsible for social attention, so it is the ideal area of the brain to be involved in this adaptation. As has been found with *Xenopus laevis*, hyper-functionality means that autistic children could quickly catch-up from the disrupted development in *advantageous* environmental conditions. From this perspective, the developmental window is not time-dependent, I propose it to be developmental stage and phase-dependent. When environmental conditions are less variable and the caregiver can be present to support the child, the delayed skills may be developed and the child may catch up.

It is proposed that autism may be a highly advantageous adaption, creating a precocious, more self-reliant, hyper-fearful and vigilant child during times of environmental adversity. When explaining phenomena, a developmental approach should be used to answer the questions of the adaptive value by understanding at specific development times. The following section moves on to discuss the potential adaptive value in adulthood

Autism Advantage in Adulthood

The hyper- fear and reactivity and enhanced sensory perception would enable the autistic adult to quickly identify danger and react accordingly. These attributes would also be of benefit when hunting for or gathering food. Enhanced perception, fear and reactivity (adapted SC and HPA axis) would enable rapid identification and response to potential prey and predators, increasing chances of survival, i.e. the enhancements lead to a greater chance of catching food and not being eaten.

Hyper-plasticity and learning, alongside the ability to immerse in an interest (Mottron et al., 2009), could enable the adult to problem-solve and develop unique or new ways of doing things. This proposal fits with Potts (2013) findings that key adaptions and abilities to change surroundings by our early ancestors are concentrated in the most prolonged periods of high climate variability as adaptive responses to instability (Potts, 2013). It has also been proposed that there is evidence from archaeology that the integration of different minds can explain modern human behaviour through social mechanisms (Spikins, 2009). Autism is used as an example of the different minds with evidence of improved technological

innovations and innovative thinking thought to have been created by an autistic phenotype (Spikins, 2009).

There has been a longstanding debate regarding the association of cave art and autism. Ancient cave art has been compared to the drawings of an autistic child, and it is proposed that cave art may have been created by autistic individuals (Humphrey, 1998). More recently, the exceptional realism found in the artworks of autistic children has been compared to the artwork of non-autistic children, who do not show exceptional realism (Spikins, Scott, & Wright, 2018). The researchers suggest that the local-processing bias[11] that has been found in autistic individuals, leads to the talent of exceptional realism from these artists. The exceptional abilities in realistic art are not always associated with autism; however, it is rare in the non-autistic population. Therefore, it has previously been proposed that individuals with a local-processing bias, who today may be identified as autistic, may have played a part in creating the European Upper Palaeolithic cave art (Spikins et al., 2018). The local processing bias to which they link exceptional realism is potentially the proposed enhanced SC.

This chapter has made a case for autism being a highly adaptive response to climate variability or maternal stress from other sources. However, as chapter two highlighted, outcomes for autistic people can be poor (Dillenburger et al., 2015) and this leads to the question: if autism is an evolutionary adaptation, why are outcomes for some autistic people so impoverished? The following section seeks to answer this through the lens of modernity, rather than ancient ancestry.

Evolutionary Adaption In the Modern World

Heying and Weinstein (2021) consider modern issues such as sleep problems, medication, and parenting, through an evolutionary lens. They propose that humans have evolved to live with nature and be plastic and adaptable to change. The rapid rate of change in the modern world has led to hyper-novelty[12] so that individuals and systems are not able to keep up with the rate of change bestowed upon us and we may have become out of sync with our world. If *Homo sapiens* in general are suffering from a multitude of ills due to the hyper-novel environment that has been created, it follows that this may also be the case for the proposed autistic phenotype.

Autistic phenotypes in ancestral (Pleistocene) environments would not have been likely to experience perceptual insults other than those that were valid threats to survival.

[11] Or enhanced functioning of the SC as proposed In this chapter.
[12] The term ‘novel’ or hyper-novel is used to describe new developments with no time for adaptation to take place.

The current Holocene Epoch is reported to be unique when more complex human civilizations and agriculture have developed with significant expansion of populations (Fritz, 2013), creating a novel Holocene[13] environment. Potentially, the Holocene environment that industrialisation has brought, brings a greater risk of stimuli overloading autistic children. The proposed enhanced threat detection system of the SC may experience constant stimuli from manufactured objects and built, unnatural environments that would distract the child's attention, and cause activation of the enhanced HPA axis and subsequent stress and distress.

From this proposed perspective of autism, attending school may lead to multiple problems. Pre-verbal autistic children would not be close to the caregiver with the opportunities to catch up on aspects of delayed development during the dyadic interactions necessary to develop these crucial skills. Instead, children may be exposed to large, noisy classrooms with overwhelming visual stimuli and lighting systems, potentially disrupting attention, activating the HPA axis and inducing stress and distress and, potentially, further disrupting development.

Another example of the modern world causing challenges to autistic children is that shops and supermarkets are now used for food acquisition. Our ancestors would have hunted for and gathered food. The hyper-visual ability would help the autistic child to be successful in these endeavours. Modern humans choose to use supermarkets or shops to gather resources, and these buildings bring intense sensory experiences to the child that may be distressing and overwhelming. Again, this might lead to a proposed advantageous adaption to become maladaptive, not because of the neurology of the autistic individual, but the environment that humans have created.

Summary

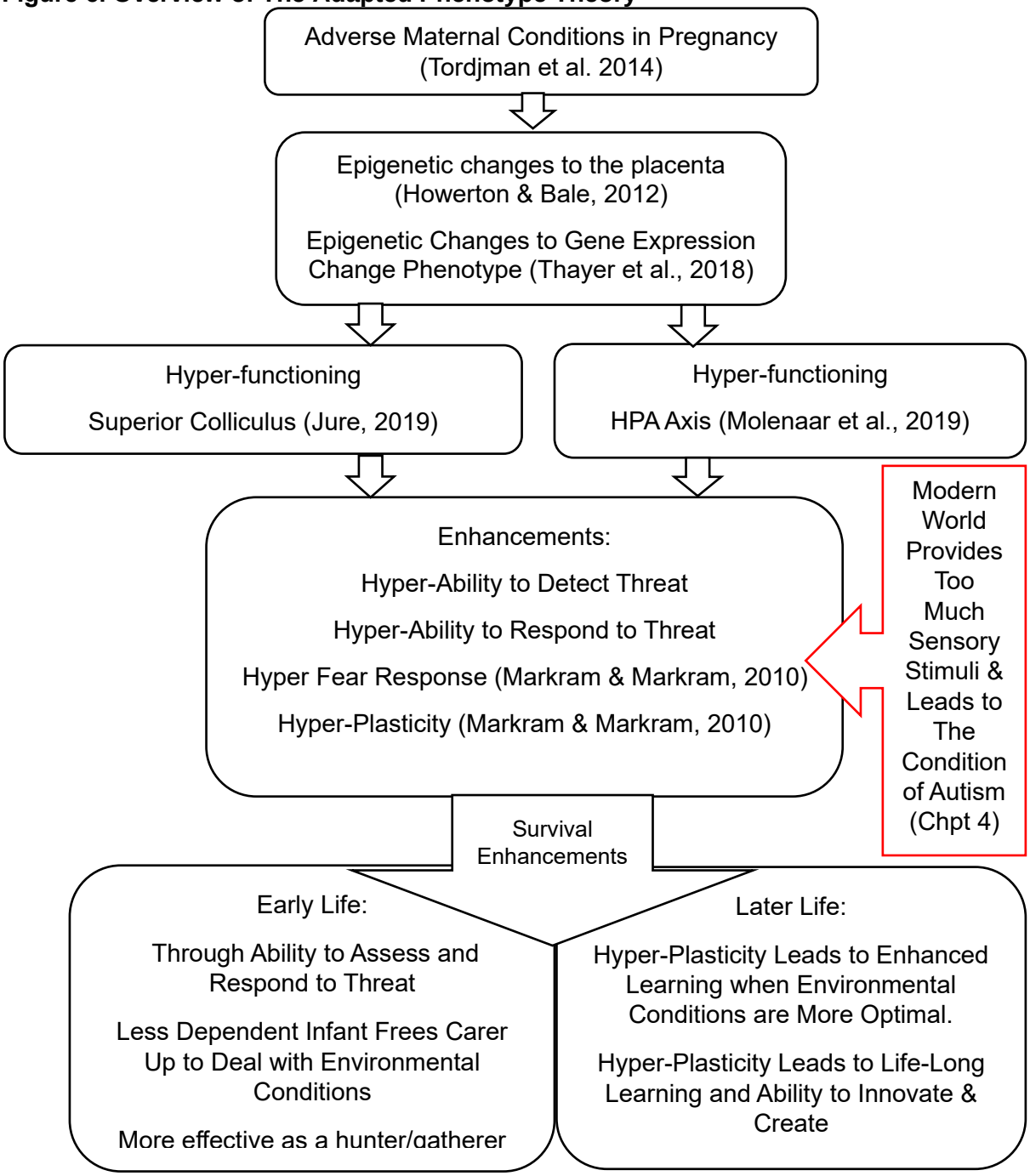
This section has drawn upon current evidence and theories to propose that autism is an evolutionary adaptation. It has been proposed that an epigenetic adaptation occurs when conditions cause a maternal immune or stress response (Beversdorf et al., 2018; Walder et al., 2014). This may cascade into prenatal programming (Howerton & Bale, 2012) of the placenta and foetus to enable the foetus to develop into an adapted autistic phenotype (Spikins et al., 2018) that is fit for the expected environmental conditions.

The proposed adaptations that enable this fitness are enhanced threat detection (SC) (Jure, 2019) and a reaction system (HPA axis) (Courtemanche et al., 2021; Meaney, Szyf, & Seckl, 2007). The chapter has gone on to propose that this adaption is shared with other

[13] Holocene is the current period of geologic time.

species (James et al., 2015; Meaney et al., 2007) and may be over four-hundred and thirty-five million years old (Kumar et al., 2017), suggesting that this is an adaptation of very high value. An overview of the Adapted Phenotype Theory is provided in Figure 6.

Figure 5. Overview of The Adapted Phenotype Theory



The Adapted Phenotype Theory described in this chapter, proposes that the modern world leads autistic children's adapted threat detection and response system to be stimulated by non-threatening stimuli. This proposed over-stimulation to non-threatening stimuli may disrupt the child's attention, create hyper-activation of the HPA axis and subsequently affect development. It has been reported that objective hardship and

subjective distress were associated with particular autism traits, and these strongly predicted autism traits in the children beyond all other predictors that were (Walder et al., 2014). However, it may be the case that the stronger the biological links the greater degree of the adaptations to the individual of the phenotype (Arnett et al., 2016).

This novel theory has value as it offers an explanation of the heterogeneity of autism and provides choices of support and intervention that may decrease sensory stimuli and aid development. Interventions and literature for parents could explain this possible adaptation and provide guidance as to how decrease sensory stimuli to avoid over-stimulation of these systems.

Potential strengths of the adaptations are that autistic individuals often exhibit deep focus and intense interest in specific subjects. This can lead to expertise and innovation in areas like mathematics, music, engineering, and technology. Evolutionarily, this may have been advantageous in societies needing specialists in tool-making, tracking, or pattern recognition. Many autistic people excel at spotting patterns and inconsistencies that others overlook. This is a strength in fields such as science, cybersecurity, and research. While sensory sensitivities can be challenging, they may also offer heightened awareness of the environment, which could have been useful in certain roles such as observational field work in ecology. In the modern world, these strengths continue to provide unique advantages in many fields.

Whilst based on current evidence and understanding, as a theory, APT is not tested. Though based on current evidence from a wide range of studies, the evidence drawn upon in the development of the theories, particularly that of the involvement of the Superior Colliculus, is based on animal studies and not human, this is a limitation. However, a strength regarding this evidence is that across the studies a variety of species were utilised. An important next step and possible evaluation of the theory could be assessing the activation of the Superior Colliculus in response to visual stimuli in the peripheral field using fMRI scanners, alongside pre-, during and post-experimentation of stress hormones in the blood. An experimental study may either lend no support to the theory or provide some support for the Adapted Phenotype Theory.

The next part of this chapter explores this concept and offers Autistic Development Theory to further understand autism and the factors that may influence development in autistic children in the post-industrialised modern world.

PART TWO:

AN ALTERNATIVE PERSPECTIVE OF AUTISM:

AUTISTIC DEVELOPMENT THEORY

Introduction

Part One of this chapter offered the Adapted Phenotype Theory which is an evolutionary perspective on the origins, nature and development of autism. The proposed enhancements of the Superior Colliculus and Hypothalamic-Pituitary-Adrenal axis may lead to disruptions to development due to the continuous activation of the systems in response to sensory stimuli encountered in the modern world. This chapter seeks to provide an overview of the factors that may influence development and seeks to further explain the heterogeneity of autistic presentations and outcomes. This is presented as an Autistic Development Theory (ADT). Developmental theories of autism are not new, what is unique is the use of the family systems and dynamic approaches to child development that offers the innovation in this thesis.

Maternal and child health professionals have been challenged to consider innovative approaches when designing, planning and implementing programmes as a response to Autism, and a suggested approach is complex systems thinking (Kroelinger et al., 2014). It is suggested that traditional epidemiologic methods have been concerned with identifying single factors so the casual effect can be identified. In contrast, a complex systems approach seeks to recognise how the system functions (Kroelinger et al., 2014). Applying causal thinking and complex systems approach to complex epidemiological challenges has been suggested to help push theoretical understanding forward (Galea, Riddle, & Kaplan, 2010). The methodology recognises that whilst there may be an isolated single cause of disease or disorder, factors at multiple levels may interrelate with each other and influence health and disease outcomes (Galea et al., 2010).

An eco-bio-developmental framework employs the fields of neuroscience, epidemiology, molecular biology, developmental psychology, genomics, sociology, and economics (Shonkoff et al., 2012). Advances in understanding the factors that promote or undermine development have led to a greater understanding of health and disease across the lifespan. Rather than the long-term view of nature versus nurture, they describe “nature dancing with nurture over time” as the process of how development is now understood (Shonkoff et al., 2012, p.3). In complex systems approaches, the dependencies between individuals are also considered as they may influence the potential impact of programmes (Kroelinger et al., 2014). To quote:

> *'Therefore, the effect of a given factor may often depend on the state of other factors in the system and be affected by feedback loops and dependencies. Understanding the fundamental relationships in the system including interactions between individuals, between individuals and environments over time, and between social and biologic processes is essential for distinguishing factors in contexts which poorly impact health. Understanding fundamental relationships is also essential for identifying appropriate intervention points to address these factors, and for anticipating the potential impact a new program will have when introduced into a specific community or "system." Successful implementation of public health interventions requires an understanding of the environment (e.g. families, communities, schools, health care system) in which the target population live and function* (Kroelinger et al., 2014. P. 3).

In this chapter, a complex systems approach has been used to gather current evidence to offer inter-related factors that may positively or negatively influence the development and presentation of autistic children.

Initially, typical child development will be briefly discussed. This is to set the foundations for understanding of some the factors that have been identified using the complex systems approach to understand autistic development.

Social-Emotional Development

When considering how autistic children's development may differ from non-autistic children, it is helpful to understand the phases of social-emotional development. Typically, autism is viewed as a social and communication disorder and concerning the development of communication, though this is just one part of the diagnostic criteria. Fogel and Thelen (1987) view communication as a developing system with a range of elements. They state:

> *'Complex skills like communication are multi-determined, incorporating elements of cognition, sensation, perception, affect, and motor control. A communicative action cannot be performed unless all of the component skills are in place and available to the individual, because the action is the system's product of the essential cooperating elements* (Fogel & Thelen, 1987, p.753).

The development of communication is dependent on the development of a variety of other skills and does not develop in isolation. Regarding general development, Lewis and Granic (2010) describe a series of stages and sub-stages of cognitive development creating foundations for phases of social-emotional development from birth to 5 years. The following section will provide a brief overview of the stages and phases that they propose.

Each stage of cognitive development is suggested to bring new phases of social-emotional development. The *'cognitive software'* for understanding the self and social world changes from stage to stage (Lewis & Granic, 2010, p. 182). Each stage brings different computations that bring specific emotional reactions and transitions when the child learns how to cope with these new emotions when they occur. Social-emotional development needs to sync with the underlying cognitive development, and this is said to occur through the generation and regulation of emotions. The social-emotional development is described as consisting of a patchwork of phases, rather than a smooth linear progression. There are thought to be periods of greater vulnerability and sensitivity mingled with other periods of greater stability, tolerance, and independence.

The first stage of cognitive development is sensorimotor consolidation, where basic regulation of the brain, body and mind occurs. Following on from this, from two and a half to four and a half months, attention is turned to people with interpersonal attention, marked by reciprocal exchanges between infant and caregiver. The Unifocal Sensorimotor co-ordination of infant's skills such as sucking, grasping and gazing occurs with new schemes to control gazing and grasping. This stage is characterised by motherese[14] and is rewarding for both mother and infant. At around four and five months, the interpersonal expectancy phase begins and is said to be a key transition in the infant beginning to understand themselves as a separate being. It is a period of early autonomy and increased interpersonal interactions with back-and-forth communication and interpersonal play, often involving expected repetitive games. A characteristic of Unifocal co-ordination is the onset of intentional behaviours – infants can act to create outcomes from around four to five months. The four-to-six-month period is said to be a time of rapid cognitive and emotional change. The following months (5 ½ -7 ½ months) see stable social-emotional development whilst the infant practices and becomes more competent with the new motor skills that have been gained. The bifocal co-ordinations stage that follows (8 – 12 months) involves the infant employing two co-ordinations, for example, a scheme for calling a parent and a scheme for the parent'' expected response. This development enables the social-emotional development of shared activities, with parents paying attention *to* the infant and *with* the infant. This development is said to be the beginning of social cognition that will eventually lead to the development of a theory of mind.

At eight- or nine-months infants learn to point to objects to direct another person's gaze, at this time infants can also direct their attention to where someone else is pointing.

[14] Motherese is a style of interacting with infants that is engaging, uses vocalisations and facial expressions to engage the infant.

During this stage, infants can retrieve hidden objects and have no longer forgotten the existence of hidden objects. Social referencing emerges as a phase of social-emotional development, where infants rely on mothers' facial expressions to cue action or inaction. For example, a frown may stop an infant from taking an action, while a smile may encourage action. The developments of pointing and social referencing are the onset of joint attention – both infant and adult are attending to the same thing, a further step towards the development of a theory of mind. This also gives rise to the infant experiencing separation distress and becoming clingier and more emotional if there is an indication the parent may leave.

The following period of motor practice (12-16 months) is similar to the motor initiative phase, with rapid cognitive development. The motor initiative phase is driven by the excitement of emerging motor skills and the development of walking, with further independence and adventures and discoveries in the non-social world. Walking requires concentration, practice and refinement over time. The substage of elaborated (sensorimotor) co-ordinations and particularly interested in reversible operations, putting things in and out of a container, turning light switches on and off, for example. It is through these reversible operations that bifocal co-ordinations are streamlined and systemised, as they continue to be the foundations of this period. Alongside the social-emotional developments is the use of single words to share wishes, thoughts and goals that help to strengthen and extend joint attention. These words allow the toddler to gain adult'' attention and have their desires met. These new capabilities may provide the child with the feeling that they are socially important and are a period of resilience, joy and independence.

The following phase (18 months) is said to bring the greatest developmental change in cognitive and social-emotional development to date. Phase seven, social negotiation, sees the beginnings of language and social relationships with parents, with an understanding of doing things together and a sense of the child being a social being who is part of a family. Advances in language mean that children move from single words to two words together and then have the ability to string words into sentences that communicate ideas and desires. At this time, it is typical for children to be observed saying the same thing repeatedly. This is said to ensure that the words used are heard by the caregiver and goals can be attained. Social roles are advanced during this phase, with the coordination of two roles that are complementary to each other, organising the relationship so it pleases both parties. When the child understands these roles, he can work out if he wants to coordinate with others or not. For example, a parent wanting to help the child get dressed in the morning when the toddler is being complimentary will offer limbs to dress. This phase also sees the understanding of goals and these may compete with the parents goals. Congruent

goals may lead to approval and positive emotion and competing goals to potential conflict and negative emotions. Further to this (17-21 months) territoriality emerges – there is a further understanding of the social order and the child's place within it. Phrases of 'No' and 'Mine' may be heard and competition to get ahead in the family and opportunity to get his/her way may be seen during this phase. The negotiation element is how much to comply, agree and behave with the social world in which the child is in. This is said to be when the independent child is also insecure and may cling to the parent to avoid psychological separation and to gain assurance. The authors suggest that this is the phase when new challenges, such as childcare, home moves or other changes to the child's routine should not take place. There is a need for closeness, shared routines, care and support during this transitional age.

The ninth phase of social-emotional development, social comparison, is from approximately twenty-eight months to three years. The cognitive substage of bifocal coordination leads to children having the ability to take one coordinated social concept, the awareness that rules can be broken or adhered to, and linking this with the concept that happiness depends on achieving your goals. This brings with it the potential power over parents' goals and subsequent emotional states, bringing social influence and capability for manipulation. Alongside this development are the beginnings of the cognitive basis for jealousy, the coordination of the ability to capture attention with the understanding that a caregiver may be attending to or helping another. This attention or focus on someone else may bring competition, your desire for attention takes it away from me. This may lead to implications regarding the basis for the caregiver's preferences – is the person receiving the attention liked more than me? This jealousy may lead to feelings of inferiority and being left out. This stage is said to have variable outcomes from child to child as external influences and the child's personality will vary the intensity and frequency of jealousy.

It is stated that the ability to generalise about ages of phases of social-emotional development becomes more difficult from this phase, with timings and types of changes becoming more individualised as children get older. It is proposed that the predictability of the earlier phases ensures that children develop basic functions to survive, but once established, there is room for individual styles to manifest into emerging personalities. From this point, it is proposed that individual profiles be considered rather than age-based averages. The second phase in the cognitive stage of bifocal co-ordination is that of family membership, with an approximate age of three to three and a half years when children accept their place within the family. This phase is said to be calmer, with children knowing the rules, how to follow them, what events cause different emotions and test boundaries

less. This is said to be a happy phase with lots of pretend play, chatter and interactions. This phase could be considered as the calm before the storm of the next phase of self-consciousness.

This final phase of early social-emotional development is the development of self-consciousness that begins for most children at around three and a half to four years old. While individual characteristics and the environment create more individualised development trajectories, an important developmental is the beginning of false-belief understanding at around 3½ - 4 years of age (Lewis & Granic, 2010. p.207). Research on the development of a theory of mind has mostly focused on false-belief understanding, which is understanding that others can be mistaken (Scott & Baillargeon, 2017). False belief understanding is proposed to be the *'crowning achievement*' in the development of a theory of mind (Lewis & Granic, 2010. p.208). A theory of mind is understanding that other people have their internal states, thoughts, feelings, opinions, and goals. The child now understands that other people's reality is not the same as theirs. This understanding is suggested to bring new insecurities and intense shame reactions. During this developmental transition children know that others have thoughts about them that may not be nice. Reactions such as not wanting to be looked at, or not wanting parents to help with the toilet are suggested to be reactions of extreme self-consciousness that may be shown in reaction to an emerging sense of shame.

A study focusing on this stage of development found that during the developmental transition when some false belief tasks were passed and others were not, children displayed shame reactions. These reactions included averting their gaze, saying sorry and putting their arms in front of their faces. In contrast, children yet to pass any false belief tasks, and those who passed with ease displayed little shame (Lewis & Granic, 2010). They suggest that knowing other people have their thoughts brings anxiety and concern over how they are viewed in the eyes of others. The anxiety is suggested to reflect self-consciousness, embarrassment, and shame. During the transition, before the child has developed coping mechanisms to deal with these new thoughts and feelings, it is proposed that the child is potentially vulnerable to decreased self-confidence, and insecurities and may have concerns about being liked or loved. This period of insecurity and sensitivity may potentially bring irrational fears, bad dreams, or concern that someone is angry about a minor misdemeanour. Children may become compulsive and ritualistic in everyday life, generating detailed rituals that need to be acted out step by step (Lewis & Granic, 2010). The type and frequency of anxiety increases during this phase and it is proposed to be a transition when children need reassurance and from the period of false-belief understanding, social-emotional challenges should be paused with any challenges to the child's sense of self avoided. The positive aspect of this development is that the shame experienced by not

meeting the expectations of others is proposed to lead to self-consciousness and behavioural adaptations. This self-consciousness is proposed to be a crucial element of children's social-moral development. The end of this phase marks the end of early social-emotional development. An overview of the stages of cognitive development and phases of social-emotional development is provided in Table 3.

Table 4. Stages & Substages of Cognitive Development as a Foundation for Phases of Social-emotional Development Across the First 4-5 Years of Life (Lewis & Granic, 2010, P.183)

Sensorimotor Consolidation (0-4 months)	
	Basic Regulation
	Interpersonal Attention
Unifocal (sensorimotor) Coordination (4-8 months)	
	Interpersonal Expectancy
	Motor Initiative
Bifocal (sensorimotor) Coordination (8-12 months)	
	Social Referencing
Elaborated (sensorimotor) Coordination (1 ½ - 2 ½ years)	
	Motor Practice
Bifocal (inter-relational) Coordination (2 ½ - 3 ½ years)	
	Social Comparison
	Family Membership
Elaborated (inter-related) Coordination (3 ½ - 5 years)	
	Self-consciousness

Key: **Cognitive Stages**, *Socio-emotional Phases*

The following sections of this chapter will identify factors that may influence autistic children's development, and how stages of cognitive development and phases of social-emotional development may be affected. Initially, a brief explanation of ADT is presented.

Autistic Development Theory

The previous chapter proposed that the core adaptions to the autistic phenotype are hyper-functioning SC and HPA axis. ADT proposes that whilst these adaptations would have been advantageous for ancestors, they can lead to developmental disruptions in the modern world. ADT also proposes that other biological systems can lead to differences in behaviour and presentation. These potential influencers are offered as factors in the following sections. The next section proposes the earliest factor that may influence development, disrupted interactions.

ADT: Factors Potentially Influencing Development: Disrupted Interactions

ADT proposes disruptions in the dyadic interactions with the caregiver and infant, due to over-stimulation of the SC and HPA axis to be a core factor that disrupts the development of social-emotional development, communication and attention in autistic infants. The current evidence that supports this proposal is discussed in this section.

The SC guides attention and mostly responds to visual stimuli from the peripheral field, as well as processing other sensory stimuli (Jure, 2019; White & Munoz, 2012). Mottron et al. (2007) identified that autistic infants, aged thirty-three to seventy-three months, display a high number of lateral (sideways) glances, mostly towards moving objects. Mottron et al. (2007) propose that these unusual behaviours may serve as attempts to regulate and/or optimise excessive local information and diminished movement perception. Taking into consideration the role of the SC, it could be argued that these behaviours may be the infant's response to stimuli from the peripheral field and the continuous activation of the enhanced SC may disrupt interactions with caregivers that provide the basis of attention and socio-cognitive development, as described in the previous section.

At birth, an infant's visual system is not fully developed and newborns have preferences for faces or face-like stimuli (Johnson, 2013). At 2-3 months, an infant's attention is captured by variations in colour or movement, while at 9 months, they show a stronger focus towards faces. This attentional difference is said to show a transition of attention towards the meaning of social stimuli (Johnson, 2013), and this corresponds with the proposed social referencing phase as described by Lewis and Granic (2010). It has been proposed (Amso, 2016) that the immature visual system in typical infants may have a developmental benefit and suggests that the development of attention is interlinked with the development of vision. The infant relies on caregivers to direct their attention to events, objects or a face, which in turn provides emotional support and information or serves to label objects. Caregivers work to gain an infant's attention and help to shape the infant's attention using a variety of means such as loud voices, gestures and colourful toys. These direct the infant's attention to the caregiver's face and teaches the infant attentional priorities and the importance of people. As discussed in the previous chapter, there is evidence that the SC is responsible for visual behaviour in the first months of life (Jure, 2019) while the visual system matures.

In a study with autistic 3- to 5-year-olds and typically developing children, they found that autistic children outperform typical children on visual attention-orientating tasks and rely more on external salient (information-giving) features to guide visual attention than controls did. It was suggested that the more mature pattern found in autistic children interferes with

the need for the infant to use adults to help with visual orienting in early life (Amso et al., 2016). This further supports infant-caregiver interactions being disrupted in early life.

The proposed enhanced SC function in autistic infants may lead to disruptions in the dyadic interactions with caregivers. A prerequisite for joint attention is the ability to follow the gaze (Thorup et al, 2016). Early joint attention is important for the development of language, for example, to learn new words children need to form an association between the object the adult is looking at and the word that is being said. Therefore, poor eye gaze is likely to impede language development. Joint attention is also important for non-verbal communication and is suggested to form the basis of later socio-cognitive development. A study of preschool-age autistic children found impairments in social orienting, joint attention and attention to distress in autistic children compared to age-matched controls (Dawson et al., 2004).

Autistic toddlers of 20 months were also found to focus attention on background objects rather than on the activities of others. Whilst spending the same time looking at people as controls, they spent less time looking at heads and more time looking at bodies. The authors suggest monitoring the social activities of other people is disrupted early in development and this limits observational learning in the future (Shic, Bradshaw, Klin, Scassellati, & Chawarska, 2011).

A review of research that focused on challenges with social orientation in autistic children found that most studies reported decreased visual attention in comparison to controls (Guilion et al. 2014). The decrease was not generalised across contexts, *increased* social content (such as additional people or adding child-directed speech) *increased* the probability of decreased attention to faces. The attention to faces is therefore likely to be context-dependent, how much additional stimuli will be a factor which helps to determine attention to faces.

Autistic infants also showed less intersubjective behaviours and social orientation in a study assessing the early interactions of autistic children and controls up to 18 months of age. Home videos were used to retrospectively analyse interactions (D. Cohen et al., 2013). Caregivers adapted their behaviour by using more touching, regulation up (to excite) or regulation down (calm) interactions. Regulation-up behaviour of the caregiver was full of 'parentese'[15] which appeared to be positively associated with the level of the infants' response (D. Cohen et al., 2013). Parents appear to naturally respond to the infant to encourage intersubjective interactions and this may play a part in the heterogeneity of

[15] Parentese refers to exaggerated speech with higher pitch and slower tempo that carers engage in when interacting with infants at particular developmental stages.

autism. That is, how successful the parents are in gaining an infant's attention and dyadic interactions may lead to varied degrees of socio-communication delay – the more successful the parent is gaining attention and subsequent interaction, the less delayed social communication and vice versa.

A systematic review of parent-infant interactions in infants at increased likelihood of autism found that the quality of the interaction in the dyad begins to diverge as early as five months old. Variables of social reciprocity, mutuality and attentiveness to parents, were predictors of later identification of autism (Wan, Green, & Scott, 2019). Parent-directed smiles usually sharply decrease at nine months old, but infants who were at increased likelihood of autism showed an increase. The authors propose that this may reflect a delay in the developmental shift from dyadic to triadic play interaction (Wan, Green, & Scott, 2019).

Delays in gestures of give and show are seen from eleven months and vocal delays become evident in the interactions from twelve months, with infants showing less speech-like vocalisation, true babbling and gestures alongside vocalisations (Wan, Green, & Scott, 2019). The first half of the second year highlighted delays in gesture use and they lacked sophistication, with high-risk infants slower to decrease non-word vocalisations and use combined vocal gesture communication. Conversely, it was found that parents may be using compensatory strategies in response to the infant'' emerging language difficulties and are found to increase verbal labelling and use more gestures. In the infants, there were also differences in emotional expression, vocal features and motor and sensory behaviours (Wan, Green, & Scott, 2019).

Differences in social-emotional reciprocity have long been accepted as part of autism. A meta-analysis of 48 studies found there is a general impairment in emotional recognition (Uljarevic & Hamilton, 2012). An online study assessing the accuracy of recognising basic emotions from photos varying from low to high intensity, found that autistic children were less accurate than controls regardless of intensity and showed the same pattern of errors as controls (Griffiths et al., 2017).

The level of emotional competence within the autistic population is varied, with some performing at typical levels and others significantly impaired with 40-64% of autistic adults displaying 'alexithymia'[16] (Bird & Cook, 2013). Bird and Cook (2013) hypothesise that the *'emotional symptoms of autism'* are due to the higher rates of alexithymia in the autistic population and that generally, people with high alexithymia have difficulty recognising emotional facial expressions and display reduced empathy (Bird & Cook, 2013, p. 2).

[16] Alexithymia refers to difficulty identifying and describing one's own emotional state.

Emotion knowledge has been linked to self-regulation and social competence, children who are more able to understand the emotional cues of others develop better social skills and interpersonal relationships in typically developing children (Trentacosta & Fine, 2010). Age-related groups of children of 6-8 years old and 8-11 years were asked to indicate which life events led to basic emotions and to describe them. Typical children in both age groups were able to give responses that showed their understanding. Autistic children gave coherent responses only in the older group and only for the emotion of happiness. The differences between the groups increased with age and were more apparent with the negative emotions (Ben-Itzchak et al., 2017). Emotion regulation and competence in basic emotions (happiness, anger, sadness) have been found in 3-4-year-old typically developing children (Denham et al., 2003). Ben-Itzchak et al. (2017) findings highlight autistic children may experience significant delays in the development of emotional understanding.

The aforementioned studies highlight the evidence that infant-caregiver interactions are likely to be disrupted in autistic infants and show an emerging pattern of delays and disruptions (Wan, Green, & Scott, 2019). Wan et al. (2019) propose that autistic infants may be delayed in the developmental shift from dyadic to triadic play interactions. The disruptions and delays may leave children spending longer in cognitive developmental stages and social-emotional phases. Delays in the development of joint attention, language and communication likely have a ripple effect; over time, autistic children become further behind their peers and as the gap widens, the delays become more apparent, as has been shown in the cited studies.

There has recently been greater recognition that girls and women are not being served adequately by the clinical criteria and diagnostic processes for autism (Lockwood Estrin, Milner, Spain, Happé, & Colvert, 2021). Girls are often missed for diagnosis which may be reflective of the current diagnostic criteria, a bias towards male behaviours or an alternative suggestion, is that females *'genuinely cope better in some way'* (Dworzynski, Ronald, Bolton, & Happé, 2012, p. 793).

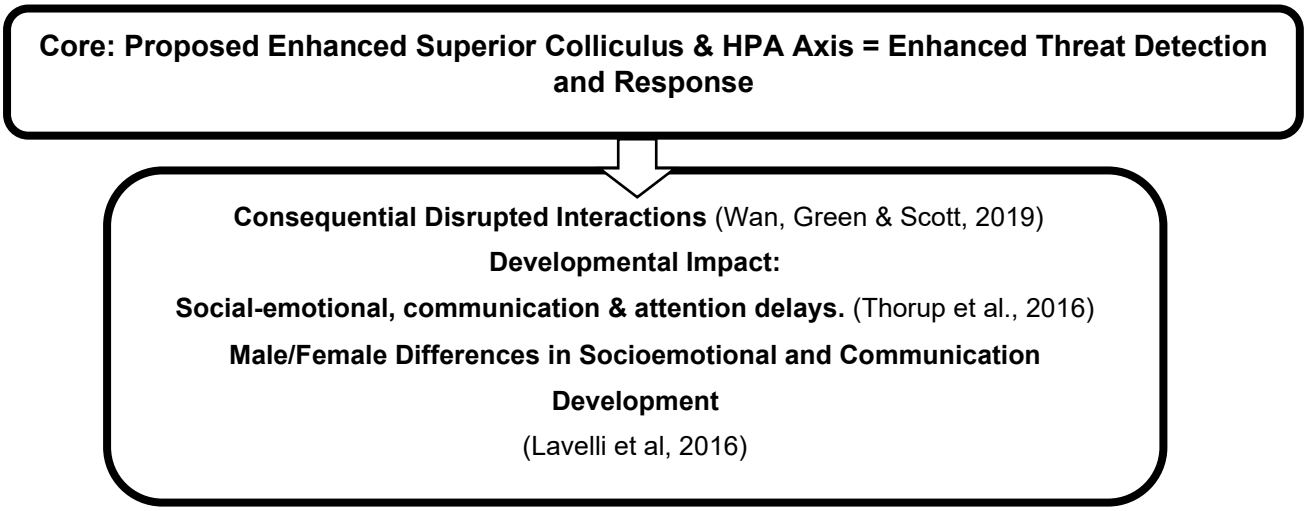
An alternative explanation is that differences in early interactions between the genders lead to differences in the developmental delays experienced in childhood. Generally, when females interact in dyads (Lavelli & Fogel, 2013) they tend to interact with their caregiver for longer periods than males. It could be argued that female autistic infants may have a greater opportunity to develop early social-emotional and communication skills because of the propensity of females to spend longer in dyadic interactions than males. This could potentially lead to autistic females presenting with different autism symptomology during childhood than males. This prospect is supported by findings of a longitudinal birth

study that found that at age seven, autistic males had more autistic social traits than females. The gender difference disappeared at sixteen, when males and females were similar, as the female'' autistic social traits had increased from age ten to sixteen (Mandy, Pellicano, St Pourcain, Skuse, & Heron, 2018).

These early interactions may begin to explain the heterogeneity of autism, e.g. less disruption will lead to fewer delays in socio-communication development. The extent to which these aspects of development are delayed will also be dependent on how much caregivers attempt to engage with the child, and how successful these attempts are.

To summarise, this section has proposed that enhancement of the SC interferes with and disrupts infant/caregiver interactions and this leads to delays in the development of attention, social interaction and communication. This proposed factor provides an evidenced-based explanation of the “deficits in social communication and interaction across multiple contexts” as specified in the DSM5 (APA, 2013). This factor sits on the model below in the arrow linking the enhanced SC/HPA axis and features of autism of social communication and attention difficulties.

Figure 6. First Overview of the Proposed Disruptions to Dyadic Interactions and the Potential Influence on Development



The following section considers the evidence that the enhanced HPA axis may lead to chronic stress.

Factors Potentially Influencing Development: Enhanced HPA Axis

There is evidence that the HPA axis is enhanced in autistic individuals (Corbett & Simon, 2014) and this concept has been discussed in the previous part of the chapter. Whilst it is proposed that this is an evolutionary adaptation to maternal stress, the hyper-activation of

the HPA axis may lead to the autistic child experiencing chronic stress or even toxic stress and this is the focus of this section.

Exposure to sensory stimuli and anxiety, alongside the enhanced HPA axis, may lead the child to experience chronic stress that may cause loss of skills (regression) and may play a part in poor developmental and health outcomes (Dillenburger et al., 2015).

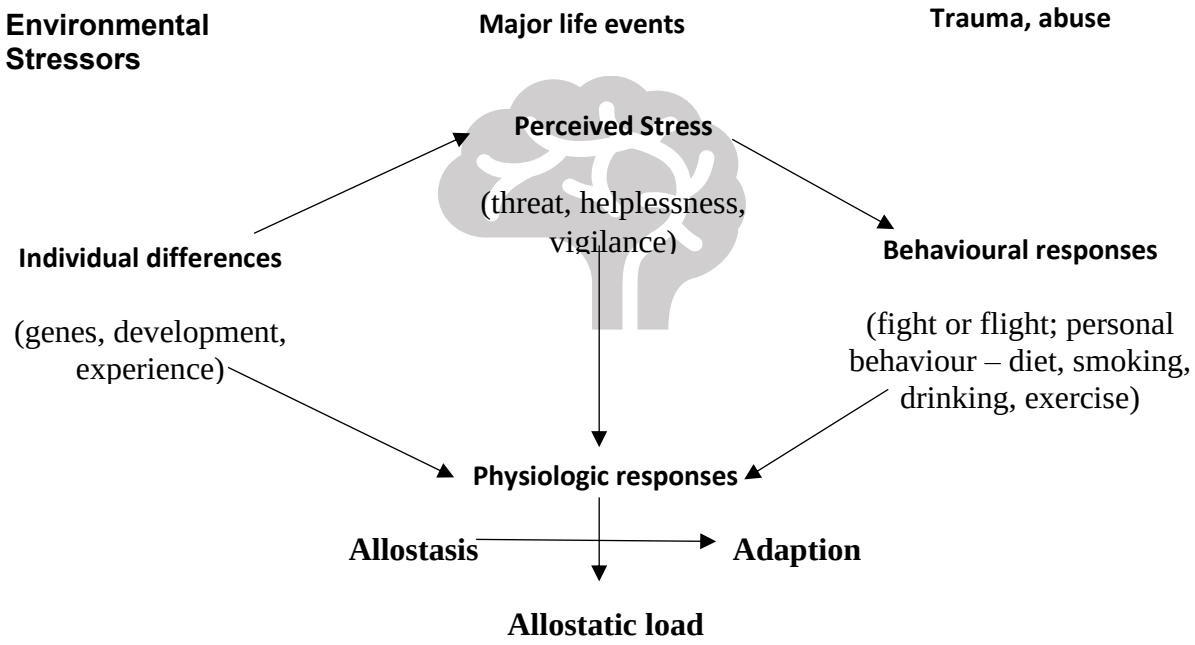
Homeostasis is the body's process of physiological regulation. Allostasis moves beyond homeostasis and considers the brain's role in feedback and whole-body adaption to contexts. Allostatic load is the consequential impact on the body of repeated allostatic responses being activated in stressful situations. The allostatic load model provides the cause and effects of chronic stress and is shown in Figure. 8 (McEwen, 2000).

The model explains how the mediators of the stress response, glucocorticoids from the hypothalamic-pituitary-adrenal (HPA) axis, and catecholamines, from the sympathetic-adrenal-medullary (SAM) axis (Juster, McEwen, & Lupien, 2010), are essential to provide energy for the fight or fight response (Juster et al., 2010; McEwen, 2000). The role of the brain is to evaluate threats and form a response. The perception of threat and subsequent activation of allostatic mechanisms are influenced by factors which determine an individual's resilience to stress. The factors are:

- Constitutional: genetics, development, experience
- Behavioural: health and coping habits
- Historical: stressful environment, trauma, abuse, major life events

Whilst adaptive and protective in the acute event, allostatic mechanisms cause damage when chronically over-activated, leading biological systems to over-compensate and eventually collapse (Juster, McEwen, & Lupien, 2010). This leaves a vulnerability to stress-related diseases for the individual.

Figure 7. The Allostatic Load Model (Juster et al., 2010)



Behavioural response to challenge provides either protective effects or damage and yields a form of allostatic load that can either increase or decrease further risk of harm or disease (Bierhaus et al., 2003; Juster et al., 2010). For example, reacting aggressively or smoking and/or drinking is more likely to increase risk than cooperation with others and a healthy diet and exercise. Cognition also plays a part in an individual's assessment of a situation being potentially stressful, and this leads the brain to initiate behaviours which may minimise threat or enhance it.

Whilst the allostatic load model is widely accepted, an evolutionary-developmental theory, the Adapted Calibration Model, of stress and health relations has been offered (Ellis & Del Giudice, 2014). This model proposes that the benefit of repeated stress responses is traded off against costs to physical and mental health. The trade-offs are proposed to be decision nodes in resource allocation and each one influences the next and becomes regulatory parameters of the stress response. It is proposed:

> *Over development, these parameters filter and embed information about key dimensions of environmental stress and support, mediating the organism's openness to environmental inputs, and function to regulate life history strategies to match those dimensions. Drawing on the ACM, we propose that consideration of biological fitness trade-offs, as delineated by life history theory, is needed to more fully explain the complex relations between developmental exposures to stress, stress responsivity, behavioural strategies, and health* (Ellis & Del Giudice, 2014 P.3).

They propose that specific protective factors such as parental bond, social support and a sense of meaning, may promote life-long resiliency and these could be targeted at critical childhood transitions by implementing programmes to cultivate resiliency and improve public health.

Brain changes associated with allostatic load are structural atrophy or hypertrophy, suppressed neurogenesis and synaptic and dendritic remodelling, which serve to further reduce the ability to cognitively process and respond to stressors. These play a part in the pathophysiological allostatic states in which response patterns show dysregulated or over-activated allostatic systems (R.-P. P. Juster et al., 2010). The model suggests that there is a chain of mediators which dysregulate, with both primary and secondary mediators leading to effects on many organ systems of the body. Biomarkers of the primary mediators are stress hormones and their antagonists and anti-inflammatory and pro-inflammatory cytokines such as tumour necrosis factor-alpha and interleukin-6. The molecules wield primary effects on cellular activity which compromise the allostatic mechanisms. In time, subsidiary systems compensate for the over/under production of primary mediators and change ranges to maintain the functions of organs, chemicals and tissues. The secondary outcomes stage sees biomarker parameters for metabolic, cardiovascular and immunity, reach sub-clinical levels. The final stage is allostatic overload where the physiological dysregulation leads to outcomes of disorder, disease and potentially death (Juster et al., 2010; McEwen, 2000).

The impact of allostatic overload on children and health in adult life has shown significant disadvantages. The eco-bio-developmental framework shows how environmental factors and early experiences can leave a legacy on genetic predispositions that affect the developing brain's architecture and may negatively impact long-term health. Shonkoff and Garner (2012) provide a conceptual classification of 3 types of stress responses in young children; positive; tolerable and toxic.

Positive stress response is a physiological state of mild to moderate extent and is brief. The availability of a responsive and caring adult to provide a protective buffering effect to facilitate stress response systems back to their baseline state is central. Positive stress is said to be a growth-promoting element of ordinary development whereby children watch, learn and practice healthy adaptive responses to adversity.

A tolerable stress response is exposure to less usual experiences, such as a death or serious illness. Experienced with buffering protection from supportive adults, the risk of excessive activation of the stress response systems that lead to long-term effects on health and learning is said to be greatly reduced. Shonkoff and Garner (2012) suggest the essential characteristics are the extent the protective adult relationships facilitate the child's sense of

control and adaptive coping, thus reducing the physiologic stress response and promoting to return to baseline status.

The stress response can result from strong, recurrent, or prolonged activation of the stress response system in the absence of the buffering protection of supportive adult relationships. The essential characteristic of toxic stress is the suggested disruption of the circuitry of the brain and other metabolic and organ systems during sensitive developmental periods. The article authors suggest the disruption may result in anatomic changes, and/or physiologic dysregulations that are forerunners for later impairments in behaviour and learning and a base of chronic stress-related physical and mental ill-health (Shonkoff et al., 2012).

Shonkoff and Garner (2012) report that the plasticity of the brain in the foetal, infant and early childhood stages, leads it to be sensitive to chemical influences. They state that there is growing evidence to show that persistently raised levels of stress hormones can disrupt the developing brain's architecture. Exposure to stressful experiences has been found to alter the size and neuronal architecture of the amygdala, hippocampus and prefrontal cortex and lead to functional differences in learning, memory and executive functioning, all of which are associated with autism. A reduction in the volume of the amygdala and hippocampus has been identified in autistic individuals and a broad spectrum of focal qualitative neuropathological developmental changes in 92% of examined brains, (Saitoh et al., 1995), while autistic differences in learning, attention and executive functioning have also been well documented (Hill, 2004; F. Levy, 2007; Mayes & Calhoun, 2007; Mesibov & Shea, 1996; Rao, Mysore, & Raman, 2016).

Further impairments resulting from toxic stress include hypertrophy and overactivity in the amygdala and orbitofrontal cortex, loss of neural connection and neurons in the hippocampus and medial prefrontal cortex (mPFC) leading to impaired memory, mood control and anxiety related to hyperactivation of the amygdala and less top-down control resulting from PFC atrophy. Additionally, the amygdala activates the physiologic stress response, and significant stress in early childhood is said to trigger hypertrophy and leads to chronically activated physiologic stress response and increased potential for fear and anxiety (Shonkoff et al., 2012). Hypotrophy and neural dysfunction have been identified in several brain regions of autistic children from a young age (Courchesne et al., 2011).

Chronic stress reduces the hippocampus' ability to switch off elevated cortisol which may lead to memory impairment. Toxic stress is also said to limit the hippocampus's ability to promote contextual learning. Shonkoff and Garner (2012) suggest that this may partly explain the association between adverse early experiences and later problems in the

development of cognitive, linguistic and social-emotional skills. They propose the consequences of chronic stress can be directly linked to the ongoing challenges with memory and learning associated with autism and the continued delay in social-emotional and functional skills.

Shonkoff and Garner (2012) suggest that the potential consequences of childhood toxic stress for the development of adult disease are considerable. They report growing evidence of a strong link between early adversity and a range of health-threatening behaviours. Biologically, there is emerging documentation of the cumulative impact of stress over time.

A 2016 paper 'Premature Mortality Autism Spectrum Disorder' reported that autistic people were at higher risk and prone to an early death, approximately 18 years earlier than non-autistic, while those who also have a learning disability, die around 30 years earlier than non-autistics (Hirvikoski et al., 2016). The study reported that autistic people are dying younger from almost every cause of death. Toxic stress may be a contributory factor to the premature mortality of autistic people. This potentially has significant implications for research and highlights a need for interventions to reduce chronic stress in autistic children and adults and promote well-being.

Allostatic overload and toxic stress in childhood provide a potential explanation for many research findings that have focused on neurological differences found in autistic individuals. Many disparate findings from autism research are explained as the consequences of chronic stress. These include, but are not exclusive of, immunology (Meltzer & Van de Water, 2017; Stigler, Sweeten, Posey, & McDougle, 2009), gastrointestinal problems (Chaidez, Hansen, & Hertz-Picciotto, 2014), delays in functional skills (Kerns et al., 2015), on-going anxiety and the onset of mental ill-health (Magnuson & Constantino, 2011; Moss, Howlin, Savage, Bolton, & Rutter, 2015; Skokauskas & Gallagher, 2012; Vasa & Mazurek, 2015).

The evidence suggests that the potentially enhanced HPA axis and factors related to the proposed enhanced SC may result in autistic children experiencing chronic stress. This has the potential to lead to toxic stress and the consequential poor life and health outcomes (Shonkoff et al., 2012).

The challenge implied by this area of research is to develop interventions which serve to alter the child's perceptions of stressors and their subsequent behavioural responses. The buffering effects of caregivers are critical to ensure that stress is either positive or tolerable and not toxic for autistic children. The buffering effects may be provided to the child in as many aspects of life as is practically possible. It therefore becomes

essential that other adults, such as teachers, harness such interventions with autistic children as well as caregivers to build resilience. Alongside this, there is a need for autistic children to have access to support that will help to decrease HPA axis activation, directly, such as controlled breathing (Jerath, Crawford, Barnes, & Harden, 2015) and indirectly by minimising the environmental triggers the SC that may induce HPA axis activation. In the next section, sex differences are discussed concerning autism presentation and stress.

Factors Potentially Influencing Development: Sex Differences may Influence Behaviour.

Female autistics are often identified late or mislabeled and there has been a recent rise in recognition that autism may present differently in males and females. It has been proposed that the female autistic phenotype may be invested in camouflaging their social difficulties to fit in. Females may tend to internalise their difficulties rather than externalise them and become disruptive, as can be the case with male autistic children. Females are also reported to have better non-verbal communication and social motivation than males (Bargiela, Steward, & Mandy, 2016). An explanation for these sex differences has been offered in the disrupted dyadic interactions section, however, a further sex difference is proposed to be the male/female stress response differences.

The behavioural consequence of stress can present as the fight or flight response (Taylor et al., 2000). Taylor et al (2000) suggest that testosterone may be the hormone where arousal of the sympathetic nervous system (SNS) channels into hostility and attack behaviour in males. It is not that females do not display aggression, females tend to engage in indirect aggression, such as gossiping or undermining others, and appear less tied to SNS arousal than males (Taylor et al., 2000).

There are three ways in which oxytocin, a hormone with a counter-regulatory role in stress, has been proposed to exhibit different physiological and behavioural responses between the sexes in animal studies. The first is that female rats show greater levels of oxytocin being released than males. Second, androgens (male sex hormones) inhibit oxytocin release under stress conditions and thirdly, oestrogen (female sex hormone) modulates the effects of oxytocin (Taylor et al., 2000).

Taylor et al (2000) propose a biobehavioural response to stress found mainly in females, which can be ‘tend and befriend’, in which ‘’tend’ is to look after others, and ‘befriend’ is to seek contact with other supportive females. It is suggested that the evolutionary roots of this bio-behavioural response come from the attachment–caregiving system. The female responds to stress by removing the infant from harm and calming the

infant. Oxytocin and endogenous opioid mechanisms modulate sympathetic arousal and HPA activation, oxytocin also reduces anxiety and has a mild sedative effect. This calms the female who is physiologically triggered by a stressor and promotes affiliative behaviour towards offspring and other females. Further to this, the effects of oxytocin are enhanced by oestrogen, and these effects are suggested to be potent and long-lasting. Oxytocin has also been linked to enhancing socio-communicative behaviours, such as eye contact (Taylor et al., 2000).

In summary, female and male bio-behavioural responses to stress may be different. Testosterone may serve to inhibit oxytocin, enhancing the fight/flight behavioural stress response, while oxytocin and oestrogen in females may lead to quicker recovery from stress and affiliative contact with infants and other females (Taylor et al., 2000). These bio-behavioural sex differences are important to enhance our understanding and support of autistic females. While childhood reports of autistic symptoms are similar for males and females, some differences are reported in adulthood (Lai et al., 2011) and this may be due to the effects of male and female sex hormones. The behavioural response to anxiety is discussed as a factor in the following section.

Factors Potentially Influencing Development: Anxiety May Lead to Simple and Complex Avoidant Behaviours

A recent study claims that approximately fifty per cent of autistic children and adults experience anxiety (Rodgers & Ofield, 2018), and this has been linked with sensory processing. This may mean that potential enhancements of the SC and HPA axis may directly influence the development of anxiety. A longitudinal study with autistic toddlers found that sensory over-responsivity remained stable over time, but anxiety increased, with higher levels of anxiety in higher-functioning children. They suggest this could be due to more awareness of the environment, and understanding and expecting unfavourable events (Green, Ben-Sasson, Soto, & Carter, 2012). A meta-analysis of studies concerned with anxiety in autistic children showd that higher rates of anxiety were found in studies with a higher mean age of participants (Francisca van Steensel, Bogels, Perrin, Bögels, & Perrin, 2011), highlighting that anxieties may increase with age.

Whilst some propose that anxiety is related to cognitive processing (Greenaway & Howlin, 2010; Hill, 2004), research has indicated that anxiety may derive from sensory differences, intolerance of uncertainty, rumination and thinking patterns (Green, Ben-Sasson, Soto, & Carter, 2012; Hare et al., 2015; Ozsivadjian et al., 2012; Pugliese, Fritz, & White, 2014; Wigham et al., 2015).

Autistic children are reported by parents to have difficulty sharing their thoughts, and their style of thinking can be negative and make anxiety worse (Ozsivadjian et al., 2012). Insight into state anxiety and the characteristics of thoughts has come from a real-time study with adults (Hare et al., 2014). They found that significantly more time was being spent on thoughts by autistic participants than those in a control group, with 22% of the autistic group spending between 5-10 minutes on thoughts, and 30% spent over 10 minutes on the same thoughts, significantly longer than controls. This is suggestive of autistic people ruminating, and negative affect rumination has been linked to the development and maintenance of mental health problems (Bijttebier et al., 2012). The Hare et al (2015) study found that state anxiety was significantly higher in the autistic group than in non-autistic controls, though anxious feelings were not associated with anxious thoughts. It was recommended that cognitive approaches may be needed to help autistic individuals to recognise and articulate anxiety-related thoughts.

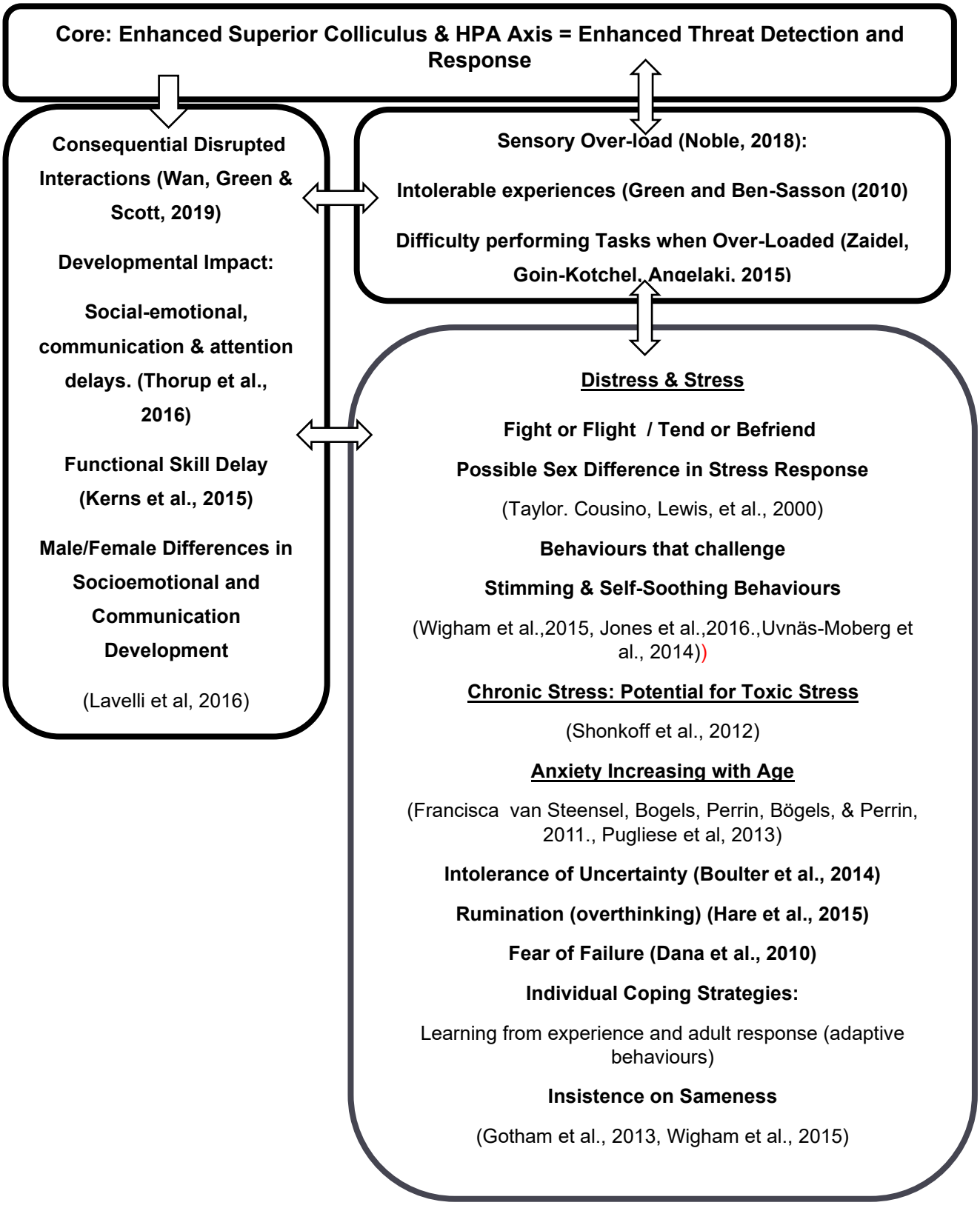
Ozsivadjian et al (2012) suggest that anxiety leads to restrictive activity, with children becoming less exposed to the world as they avoid more experiences to prevent situations that are perceived as confusing and threatening. These restrictions may serve to compound the delays that are experienced by autistic children. How sensory processing impacts how autistic individuals experience the built environment was the focus of a study that found autistic people consistently reported higher levels of discomfort in their workplaces and homes. They felt discomforts that were more overwhelming, stressed, distracted and less safe than those in control (Noble, 2018). Shopping centres, supermarkets, retailers and medical buildings caused greater distress and discomfort than controls, with the odds of autistic individuals avoiding these buildings reported as 8.8 times greater than controls (Nobel, 2018). This finding is indicative that autistic individuals may be avoiding situations and environments that could induce stress and distress.

It is possible that in response to sensory overload and anxiety, children will develop strategies to avoid exposure and these strategies may be a result of their unique character, individual experiences, and the response from caregivers and the environment. For example, an autistic child is experiencing too much sensory stimuli in the supermarket and it is intolerable and the child becomes stressed, so screams, kicks and punches to express the distress being felt. The exasperated caregiver does not have the resources to deal with the situation and leaves the supermarket with the child. The child's world is now tolerable, and the behaviours may become a good strategy to use to avoid future distress. Next time, the child may scream, kick and punch before entering, to avoid perceptual overload and distress. ADT proposes that these adaptive behaviours may be an attempt to control their

environment and experiences that may manifest in apparent inflexibility, a need for sameness and routines as well as behaviours previously discussed.

Behaviours described in the DSM5 (APA, 2013) under restricted, repetitive patterns of behaviour, interests or activities, are stereotyped or repetitive motor movements, and unusual interests in sensory aspects of the environment. These potential behaviours may also be linked to anxiety. Repetitive motor movements have been described by autistic adults as 'stimming' and are reported to serve as a self-regulatory mechanism that lacks social acceptance from others (Kapp et al., 2019). Generally, humans engage in a variety of behaviours to relieve tension, and stress and to feel better. Oxytocin is released when sensory nerves are activated and is associated with strong anti-stress effects (Uvnäs-Moberg, Handlin, & Petersson, 2014). Oxytocin is involved with self-soothing behaviours, through low-intensity somatosensory stimulation triggering its release. The types of behaviours and interactions involved in self-soothing can be touch, massage, warmth, interactions with others, stroking dogs and suckling-related behaviours. The effect of oxytocin decreases stress and increases well-being and calmness. Oxytocin is also said to increase eye-gazing and the ability to interpret facial expression, and tone of voice and to facilitate social interaction (Uvnäs-Moberg et al., 2014). Autistic individuals may engage in stimming as it decreases stress, induces calm, and may support interactions with others. Taking this perspective, stimming may be viewed as a positive occurrence that supports the well-being of the autistic individual. The onset of anxiety may be a significant contributory factor in the development of simple to complex avoidant behaviours throughout childhood and may also lead to self-soothing behaviours in autistic individuals. These factors

Figure 8. Factors Potentially Influencing Development, 1



and potential sex differences are visually represented in Figure 9. which are discussed concerning child development in general.

Factors Potentially Influencing Development: Right Behaviour, Wrong Time

In this section, it is proposed that some behaviours and challenges associated with autism are typical features of development, though appear atypical because of the chronological age of the child when the behaviours emerge. ADT proposes that several behaviours viewed as 'autistic' are developmentally appropriate and transitory. Research findings have previously found in a longitudinal study that autistic children's Theory of Mind and Executive Functioning improved over time (Pellicano, 2010), highlighting that challenges in these areas may be developmental rather than life-long.

Regarding language development, some features described as stereotypic autistic behaviours, are typically found in children as part of ordinary development. For example, using gestures rather than words is a normal feature of language development. Items being gestured to lead to verbalisation of the items to form new words (Iverson & Goldin-Meadow, 2005). Another example is that of echolalia (repeating the words being said either immediately or later), which is said to be an autistic characteristic. Imitation is involved in the development of syntax [17] that usually forms in the second year of life when the child transitions from single words to sentences (Clark, 1977). Echolalia could therefore be a transitory manifestation of a stage in language development but may appear pathological because the transition occurs in autistic children at an older chronological age than typically developing peers.

Six stages of natural language development in autistic children have been identified. This begins by using unmitigated echolalia (repetitive use of a whole sentence), which turns to mitigated echolalia (altering the sentence) (Stiegler, 2015). This stage is followed by the use of single words, and then two-word phrases. The following stages are the formation of sentences that become more complex with advances in grammar. This highlights the transitory nature of echolalia which may be considered a temporary form of communication during the development of functional language.

Another developmental transition that may be disrupted and manifest at an older chronological age than is typically the case, is that of self-consciousness, which has previously been discussed in the social-emotional development section. Disrupted development in autistic children may lead the child to experience this phase at an older chronological age. The typical behaviours and fears described due to intense shame (anxiety, fear of failure, night terrors, rituals, obsessions, extreme self-consciousness) may appear atypical as they may occur later in childhood than would be expected. A study that

[17]The arrangement of words to develop well-formed sentences.

supports this notion looked into autistic adolescents and risk-taking and found task performance was related to fear of failure (South, Dana, White, & Crowley, 2011). This developmental transition may also explain specific presentations of autism. For example, children displaying Pathological Demand Avoidance syndrome (PDA), regarded as a sub-group of autism, are not able to tolerate demands and may utilise social influence to avoid demands and control their experiences (Newson, Le Maréchal, & David, 2003). It is possible that during the transition of the development of self-consciousness, these children may use their influence as a strategy to avoid the possibility of failing or being judged in the eyes of others and excessively avoid demands that would lead to these feelings and insecurities.

This section has considered how some behaviours and presentations that have been considered unique to autistic children may be developmentally appropriate and transitory. The next section will consider the possible parental influences.

Factors Potentially Influencing Development: Parental Influences

Elevated stress has been well-documented for parents of autistic children (Da Paz, Siegel, Coccia, & Epel, 2018; Weiss, Cappadocia, Tint, & Pepler, 2015; Zablotsky, Anderson, & Law, 2013; Zablotsky et al., 2012) and this may impact their children's well-being. A longitudinal study found that parent stress and distress have been associated with autistic children's 'problem' behaviours which may be internalised (withdrawal, anxiety and fearfulness) or externalised (aggression, self-injury, tantrums and non-compliance) (Zaidman-Zait et al., 2014). Parental state anxiety has also been correlated with parental reports of their adolescent's anxiety (Conner, Maddox, & White, 2013).

Parents may also become over-involved in children's self-care tasks, choosing to undertake tasks themselves rather than the child (Drahota et al., 2011). Parents report that they found it difficult to teach their children these tasks and preferred to undertake them for the child, with the children rarely challenging this. It is suggested that parental over-involvement limits the child's ability to master some tasks, and this may lead to over-reliance on the parent and serve to maintain anxiety and disrupt the development of skills (Drahota et al., 2011).

Parental over-involvement has also been specifically linked to separation anxiety in children with an anxiety disorder (Wood, 2006). The relationship between depression and anxiety in autistic adolescents and the mood symptoms of their mothers has also been explored (Mazefsky et al., 2010). The study found that 32% of autistic adolescents met the criteria for a history of depressive disorder and 39% an anxiety disorder. They found a relationship between the mother's symptoms of depression, anxiety, phobic anxiety, hostility, and interpersonal sensitivity were co-morbid with depression and anxiety within the

adolescents. Specifically, maternal measures of anxiety were predictors of co-morbid depression in children.

The studies show a link between the well-being of parents and children and this can also influence the development of life skills that are essential for independent adult life (Drahota et al., 2011). However, the researchers also found that cognitive behavioural therapy (CBT) for anxiety was found to increase the children's daily living skills and reduce parental involvement in the children's self-care tasks. The researchers concluded that CBT may have promoted skill development in children whilst encouraging parents to support and encourage the use of new skills.

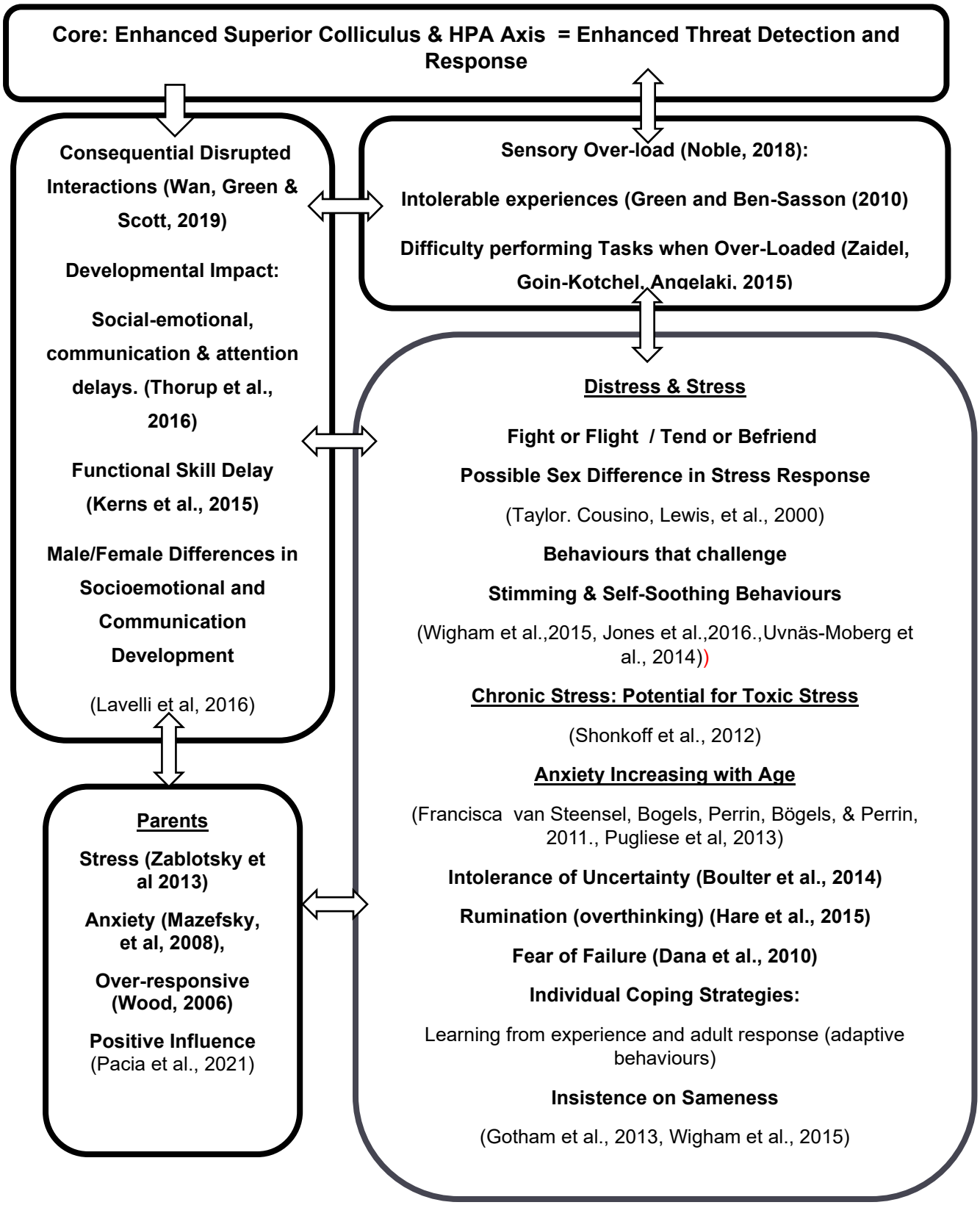
Other studies have also shown that parents of autistic children may positively influence their child's development. PACT (preschool, parent-mediated social communication therapy) for young autistic children, found that autism symptoms were reduced as a result of these interventions and the effects were still apparent after six years (Pickles et al., 2016). There is a valid argument that this reduction is feeding a deficit-focused model of autism and, therefore, an outcome of "symptom" reduction is not helpful or positive.

Parent-mediated interventions are commonly used and a systematic review of fifty parent-mediated interventions and four sibling-mediated interventions found that most studies reported skill gains for some children (Pacia, Holloway, Gunning, & Lee, 2021).

These studies (Pacia et al., 2021; Pickles et al., 2016) show that parents can positively influence their children's development and provide interventions to decrease the symptoms of autism when they are given appropriate support and guidance. The findings of Drahota et al (2011) indicate that merely highlighting their potential over-involvement, in their children's life skill delays, may lead parents to become more aware of the need to encourage the development of these skills in daily life. Figure 10. below shows the possible parental influences on the child's development.

The following section considers the potential impact of mental health diagnoses on autistic children's development.

Figure 9. Factors Potentially Influencing Development



Factors Potentially Influencing Development: Mental Health Diagnoses and Prescription Drugs

This section aims to consider the potential impact of co-morbid mental health diagnoses and medications on the development of autistic children.

Autistic children are said to experience higher rates of Attention Deficit Hyperactivity Disorder, behavioural issues, lower overall happiness scores, reluctance to attend school, and experience higher levels of bullying and social isolation (Dillenburger et al., 2015). Autistic children frequently experience one or more co-morbid conditions and a number of these are psychiatric in nature (Close et al., 2012; Gadow et al., 2008; Garcia-Villamisar & Rojahn, 2015; Levy et al., 2010; Mattila et al., 2010). A meta-analysis of 96 studies found a 28% diagnosis of ADHD, 20% anxiety disorders, 13% sleep cycle disorders, 9% obsessive-compulsive disorders, 12% disruptive disorders, 11% depressive disorders, 5% bi-polar disorders and 4% schizophrenia disorders (Lai et al., 2019)

Depression is commonly reported within the autistic population. A study by Strang et al (2012) found that 30% of autistic individuals aged 6-18 years, had depressive symptoms within the clinical range of depression and 40% presented with borderline levels of symptoms. They reported that autistic children and adolescents are at an increased risk of depression and/or anxiety regardless of IQ, age, or autism symptomology. A review of literature attempting to find prevalence rates of depression in autistic children, found rates of depression ranged from 1.4% to 38% (Magnuson & Constantino, 2011).

Peer relationships seem to be a particularly important factor in the development of depression (Williamson, Craig, & Slinger, 2008). Peer approval, or its absence, can be a predictor of the condition. Self-perceived peer approval and social competence are also suggested to predict global self-worth scores (Williamson et al., 2008). There appears to be an increased risk of autistic boys developing depression and the risk increased when there was a second co-morbid condition, such as ADHD. Findings also suggest that when depression occurred in children with two or more mental health conditions, the symptoms were of greater severity than in children without a co-morbid condition (Gadow et al., 2012).

Utilising data from the Millennium Cohort Study, a study has found that the timing of autism diagnosis was related to depression and self-harming. Children who were diagnosed with autism after the age of eleven experienced the highest rates of depression and self-harming at fourteen years old (Hosozawa, Sacker, & Cable, 2021). The authors propose that the lack of early intervention and appropriate support may be involved or increased rates of bullying-victimisation that the children experience.

A study looking at pharmacological treatments in primary care using the medical records of 5651 autistic patients under 25 years in the UK, aimed to find the pattern of prescribing in the population (Murray et al., 2014). Nine categories of drugs were defined, these are presented in Table 3. The groups of medications most prescribed were found to be stimulants, antidepressants, antipsychotics, sleep medications and benzodiazepines, which are a class of sedatives.

Table 5. Drug Groups Prescribed to Autistic Children & Adolescents (Murray et al., 2014)

Drug Group	% of autistic patients prescribed
Stimulants	27.5
Anti-depressants	21.6
Anti-psychotics & mood stabilisers	25.6
Benzodiazepines	22
Clonidine	1.9
Sleep medication	34
Beta-blockers	2.2
Other	4.8
Anti-parkinsonism	2.7

Murray et al (2013) also found that in 2008, 33.8% of autistic patients who were prescribed psychotropic medications were prescribed two or more drugs. This pattern is reflective of that of the USA where Spencer et al. (2013) found that 35% of autistic children had poly-pharmacy of two or more drugs, with 15% being prescribed 3 or more medications. A very large study of medical records in the USA found that 64% of the 33 565 children with ASD were prescribed at least one medication.

The prescribing rate of psychotropic medication in the USA was found to be 64%, highlighting that the UK is taking a more conservative approach to medication with prescribing rates being reported as 25.6%. Of these drugs, within the UK, Murray et al. (2014) found that one-fifth of the cohort who were prescribed antipsychotics were given risperidone. While risperidone is licensed in the USA for irritability in ASD, the drug is not licensed for use with autism in the UK. The use of medications has been linked to less optimal outcomes, (Markey et al., 2014) therefore, there is a need for the assessment of the long-term efficacy and safety of using such drugs in this population.

While prescribing rates of this category of medication in the UK are lower than in the USA, there is concern from the NHS regarding the use of psychotropic medication within the autistic population (Branford et al., 2019), and the long-term safety and efficacy. Markey et

al. (2015) comparing life histories of optimal outcome individuals in “high-functioning autism” found greater rates of antidepressants and antipsychotics in the “high-functioning autism” group. ADT raises further concerns regarding polypharmacy and the long-term safety of the combinations of drugs being used and potential interactions between the medications that may affect autistic children’s development. The functional connectivity patterns were assessed using fMRI of autistic children and adolescents who were currently taking psychotropic medications (stimulants, antidepressants, antipsychotics and anxiolytics). The medicated group showed underconnectivity between the cerebellum and basal ganglia and corticocortical overconnectivity compared to the non-prescribed non-autistic and autistic group controls (Linke, Olson, Gao, Fishman, & Müller, 2017).

It is worth noting that anti-psychotics are generally prescribed to reduce perceived behaviour problems (aggression and hyperactivity) presented by autistic children (Luby et al., 2006), rather than responding to a co-morbid mental health problem. A systematic review of studies comparing the use of antipsychotics to placebos found that they were effective in reducing stereotypic autistic behaviours, but not anxiety or self-harm (D’Alò et al., 2021). A paper considering the role of antipsychotics in the behavioural management of autistic children reported side effects of weight gain and hyper-salvation, with a risk of developing dyskinesias (abnormal involuntary movements) (Malone & Waheed, 2009). A study of preschool autistic children who were prescribed risperidone found that weight gain, hyper-salvation and abnormally high levels of prolactin in the blood were side effects (Luby et al., 2006). However, the children did not produce breast milk. Rats were exposed to antipsychotic medication in either the foetal stage or what would be considered early childhood in humans. They were found to have reductions in dendritic length, branching complexity and spine density in the medial prefrontal and orbital cortex of the brain. A later study found that use in adolescence caused long-lasting changes in neurotransmitters (Xu, Gullapalli, & Frost, 2015). It could be argued that current evidence is indicative that the risks of prescribing anti-psychotics for behaviour management of autistic children outweigh any perceived or evidence-based benefits. The medications may have lasting consequences on the autistic child’s brain (Linke et al., 2017) that have the potential to negatively impact life outcomes for the child.

The following section reports other external factors that may influence autistic children’s development.

Figure 10. Factors Potentially Influencing 2.

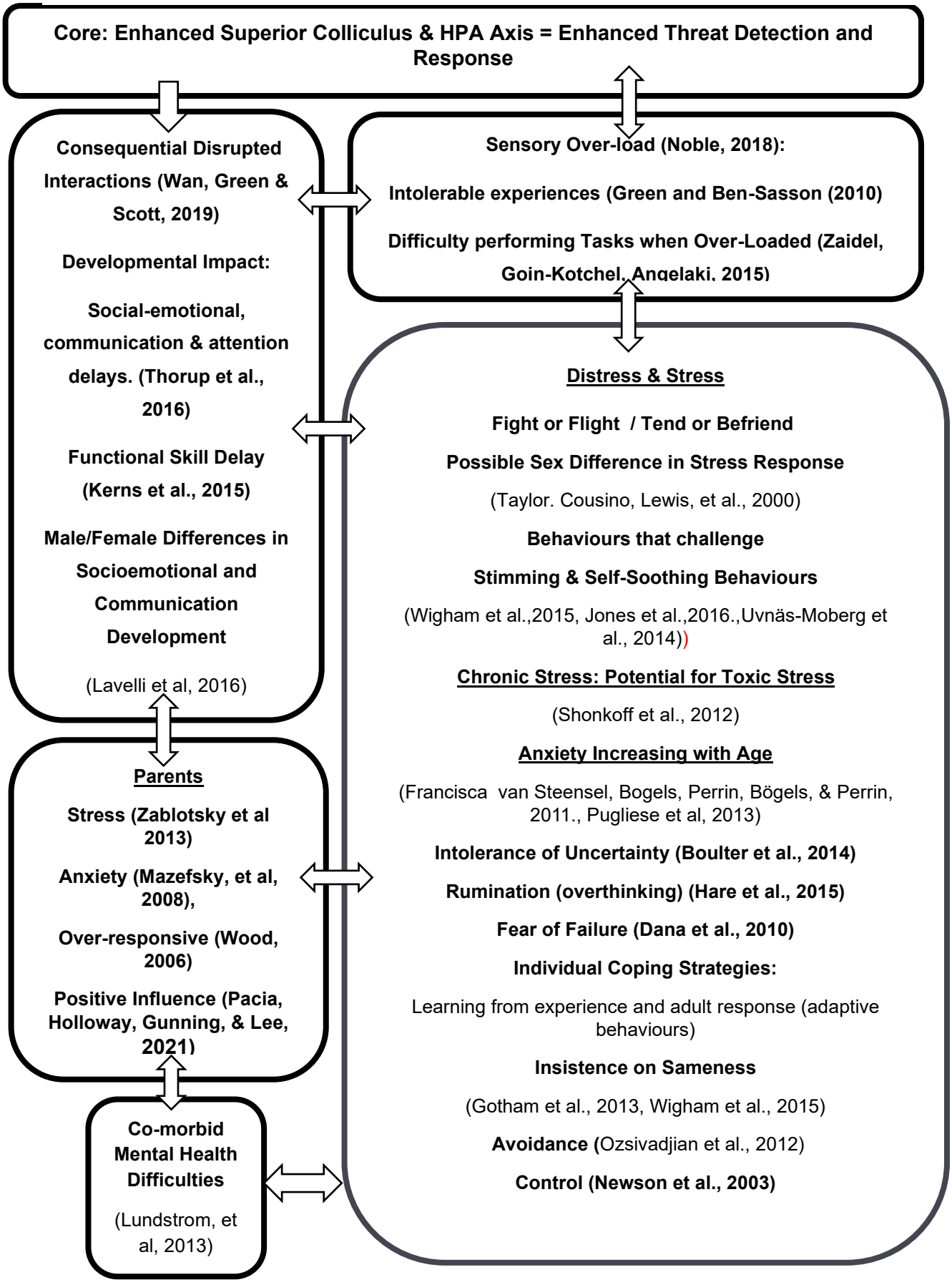


Figure 10

Factors Potentially Influencing Development: External Influencers

Data from the Millennium Cohort study has provided a great deal of insightful information on the lives of autistic children and their families (Dillenburger et al., 2015). The families were identified as having considerably higher levels of unemployment and deprivation due to issues related to caring for an autistic child. The report concluded that autistic children and their families face poor economic and mental health outcomes that increase over time.

At 5 years of age, autistic children enjoyed school less than peers and were more likely to be reluctant to attend. At the ages of 5 and 7 years, being autistic was strongly associated with not having any friends outside of school and bullying had occurred several or many times by 7 years of age (Dillenburger et al., 2015).

A further contributing factor may arise from educators. The 'Pygmalion effect' is well documented (Friedrich, Flunger, Nagengast, Jonkmann, & Trautwein, 2015) and highlights how the expectations of others can impact children's performance. People perform better when expectations are higher, therefore, limited expectations and negative attitudes of educators towards autistic children may serve to limit autistic children's development and educational attainment. The survey discussed below highlights how teacher expectations may differ for autistic pupils in comparison to non-autistic peers.

A US survey of teachers of autistic students found that many experienced most of their education outside of mainstream education. The teachers did not expect them to attain grade level standards, despite the majority of autistic students experiencing mild or no cognitive impairment (Witmer & Ferreri, 2014). The study also found that the most common goals in autistic children's Individual Education Plans were related to communication skills and behaviour rather than academic attainment. Further to this, an experimental study explored teacher attitudes to autistic children (Chung et al., 2015). Two scenarios were read by participants who were teachers, one featured an autistic student, the other a non-autistic student and participants indicated their attitude towards each. While the authors reported that teachers' attitudes were generally positive for all students, attitudes towards autistic students were significantly more negative than those for non-autistics. Teachers were more likely to dislike and avoid autistic students, with secondary school teachers more likely to have negative attitudes towards autistic students than teachers of younger children (Chung et al., 2015).

The two studies discussed in the previous paragraph highlight that an autistic child's inclusion and attainment may be adversely impacted by teacher expectations and attitude, with some autistic children experiencing exclusion from school as well. A study examining autistic students experiences of school exclusion found that parents reported that schools

were letting their children down, and they had to fight for their child's difficulties to be recognised and to gain access to appropriate support (Brede, Remington, Kenny, Warren, & Pellicano, 2017). Some parents also reported that there was a lack of understanding of their children's behaviours and the demands placed on the child caused 'massive anxiety and distress' (Brede et al., 2017 p.7). Parents and young people also reported inappropriate methods by staff, with some alleging emotional and physical abuse of their children. There were also concerns over the amount of physical restraint used on the child, which led to mental health detriment. Parents described a state of crisis, with some reporting children's self-injury, self-harm and suicide attempts (Brede et al., 2017).

Inadequate or misdirected support or inappropriate placements in educational settings that do not meet the child's needs may cause escalating stress, distress and anxiety for the child and may further disrupt development and educational attainment. Highlighting this a study with teachers found they reported autistic students displaying more emotional and behavioural difficulties than their peers and rated 54% of autistic students as under-achieving academically in comparison to 8% of non-autistic students (Ashburner, Ziviani, & Rodger, 2010).

Conversely, when autistic children are enabled to access their special interests in an educational setting, there are extensive benefits (Wood, 2019). A study found that engagement with interests led to improvements in access to learning, curriculum and tests, completion of tasks, improvements in communication and socialisation and increased independence. The author suggests that enabling autistic children to access their interests was '*the lynchpin to their very participation in school life, being linked additionally to expertise and positive outcomes in the future for the autistic children,.* (Wood, 2019, p.12).

Therefore, participation in education can be potentially detrimental to the autistic child, or highly advantageous to their well-being and future outcomes. The difference in outcomes for the child may be influenced by the expectations and attitude of the educators, the application of appropriate supportive strategies and whether the child is enabled to engage in special interests to access the curriculum and school life. The context in which an autistic child is placed is discussed in the following section.

Factors Potentially Influencing Development: Affectedness is Context Dependent

Autism has long been considered a spectrum, and diagnosticians may assess the level of severity at the point of diagnosis (APA. 2013). Generally, the concept of a spectrum of affectedness, as is currently the case, is unhelpful as it may create assumptions about a child's future progression. Assessing an individual by degree of affectedness may limit beliefs about development potential. Conversely, this section proposes that autism affectedness is not on a spectrum of severity per se, but dependent on the context that an individual finds themselves in. The proposed enhanced SC and HPA axis will be impacted by environmental stimuli, the more stimuli, the greater the impact on the individual and their ability to function and learn in that context. Therefore, it is the quality of the person/environment fit that is crucial for an autistic individual if they are to flourish.

For example, the task of being able to read text out loud and learning the content will be dependent on what environmental stimuli the individual is being exposed to and how overwhelming it is experienced by the child. The same autistic child will experience a different learning outcome if the task is undertaken in a rush hour tube station than in a calming woodland. This is of course, true for all children, however, the autistic child would be more intensely affected than non-autistic peers. Therefore, affectedness is not fixed and stable on a spectrum from low to high, rather an individual will be positively or negatively affected by exposure to either soothing or overwhelming stimuli. This is of course the case for most people, however, this thesis has proposed that the SC and HPA axis are enhanced in autistic individuals and this would likely lead to greater impacts from environmental stimuli.

The SC has also been shown to be responsible for social attention and visual attention to faces (Jure, 2019). Perceptual hyper-sensitivities have been associated with an increase in attention to stimuli of important sensory features (of faces) and these tend to be exhibited in naturalistic settings (E. J. H. Jones, Dawson, & Webb, 2017). It is proposed that in the context of a supportive environment, hypersensitivity may support social development in autistic children, rather than hinder it. In the study, the researchers ensured that children were not experiencing stimuli that were beyond their tolerance. They note that less supportive environments may compromise development by leading children to withdraw (Jones, Dawson, & Webb, 2017). This study highlights how the enhanced perception can be both a benefit for autistic children, helping them to learn and be a strength to harness, as well as a challenge, leading to withdrawal if the environment is experienced as intolerable.

A further study that focused on sensory perception, conducted multisensory tasks of self-motion perception (Zaidel, Goin-Kochel, & Angelaki, 2015). By manipulating task difficulty of random dot visual motion stimuli, independently of visual stimulus noise, they

tested the hypothesis that increased sensitivity to noise is characteristic of autism. They found perception of visual motion was not impaired without noise, but the addition of noise significantly affected autistic adolescents task ability. Additionally, they found that autistic individuals used a different strategy to control, with less use of prior knowledge and inflexible predictive abilities, which are usually learned and updated through experience. They suggested that poor predictive abilities may lead autistic individuals to rely more on sensory information and less use of prior knowledge. The findings led them to question theories of deficits in the integration of local elements or multiple senses into a global percept, such as weak central coherence theory (Frith & Happe, 1994, discussed in Chapter Two) and propose that deficits in coherent motion perception are not resultant of spatial integration impairment, but from sensory noise. It could be argued that the findings of less use of prior knowledge, learned and updated through experience, are a consequence of the potentially enhanced SC and HPA axis. Animal studies have found that tadpoles exposed to VPA did not habituate[18] to sensory stimuli as discussed in the previous part of this chapter (James et al., 2015).

Over-exposure to sensory stimuli for the autistic individual is likely to cause problems functioning and subsequently negatively impact learning and development. It is important to ensure that the person/environment fit is good so autistic children may be able to access opportunities. However, children should also be taught strategies to manage their experiences to ensure they are not under-exposed to life opportunities as this could also limit development. A further influence on developmental trajectory and presentation is that of interests, which is discussed in the following section.

Factors Potentially Influencing Development: Interests Are Motivating and A Strength

Mottron et al (2009) consider enhanced perception to be involved in the development of savant abilities and special interests. They propose that autistic individuals show an enhanced ability in pattern detection and are drawn to them. Repeating patterns are often found in structured materials and interaction with them may lead to a special interest: the material becomes associated with positive emotions and leads to an increased preference towards similar patterns. Repetitive play associated with autistic children usually groups information or objects and is also associated with positive emotions (Mottron et al., 2009, 2006). Flow experiences are those which lead us to lose track of time and to become fully immersed in our activity (Csikszentmihalyi, 2000; Mirvis, 1991). This immersion or engagement leads people to ‘switch off’ the outside world with full focus on the activity.

[18] Habituation is a diminished response to repeated exposure to stimuli.

Autistic individuals are also more motivated by intrinsic interest, knowledge, flow and engagement than controls, with some intrinsic motivational factors being associated with positive affect (Grove, Roth, & Hoekstra, 2016).

Findings from a review of thirty-one studies of interventions with children found that harnessing interests within interventions has the potential to evoke positive change. Improvements have been found in the areas of adaptive behaviour, social communication, and play.

Special interests may be considered a positive aspect of development, potentially bringing opportunities for the child to be intrinsically motivated to learn and engage. Providing autistic children with the opportunity to expand their interests may enhance opportunities and life outcomes as well as have a positive effect on well-being.

Summary and Conclusion

This chapter has proposed the Adapted Phenotype Theory (APT) and Autistic Development Theory (ADT). A complex systems approach and eco-bio-developmental framework have been used to draw on current theories and research to propose a causal and comprehensive theory of autistic development. ADT considers the core features to be an enhanced SC and HPA axis, which alters the developmental trajectory, leading to disruptions and delays in social, emotional and communication skills from infancy. A strength of this theory is that it draws on evidence from numerous studies. However, a limitation is that the theory is untested. Further investigation could test this using an observational, longitudinal study harnessing the predictive power of the theory, that may support or refute it.

This chapter has proposed other factors that may lead to different developmental trajectories, presentations, and consequential outcomes. The ADT model (Figure 12.) shows the interplay between these factors and the potential for increased challenges and delays over time, or for opportunities to be exposed to tolerable environments and suitable learning opportunities that may enable children to reach their developmental potential.

Differences in presentations and phenotypes as discussed in the previous part of this chapter, may also be understood from the perspective of ADT. The influences of individual characteristics and hormones in response to stress and anxiety may lead to different behavioural presentations and adaptive responses. The response of caregivers / educators to the child's distress, stress and anxiety may serve to reinforce, minimise or relieve the child's perceptions and behaviours. Caregivers' perceptions will also feed into the loop as parental stress, anxiety and over-responsiveness may reinforce and serve to increase child anxiety and consequential behaviours.

Approaching autism from the perspective of ADT may give rise to greater expectations for development and life outcomes. This, coupled with a deeper understanding of the roots of autistic children's difficulties, brings the possibility of many more children facing less challenges in the future than is currently the case. Integrating research into a developmental framework brings the opportunity to understand individual differences and provide individualised support to the child and family.

Taken together, the literature reviewed signals a clear paradigm shift in how autism is conceptualised, understood, and supported. Traditional deficit-oriented models, which have historically dominated both research and practice, are increasingly challenged by perspectives that emphasise relational, contextual, and strengths-based understandings of autistic experience. Neurodiversity theory reframes autism as a legitimate form of human variation, foregrounding the importance of acceptance, identity, and the role of disabling social environments rather than intrinsic deficit alone. In parallel, intervention approaches such as Paediatric Autism Communication Therapy (PACT) reflect a movement away from attempting to "normalise" the autistic individual, instead focusing on adapting interactional contexts—particularly caregiver–child relationships—to better support communication and mutual understanding.

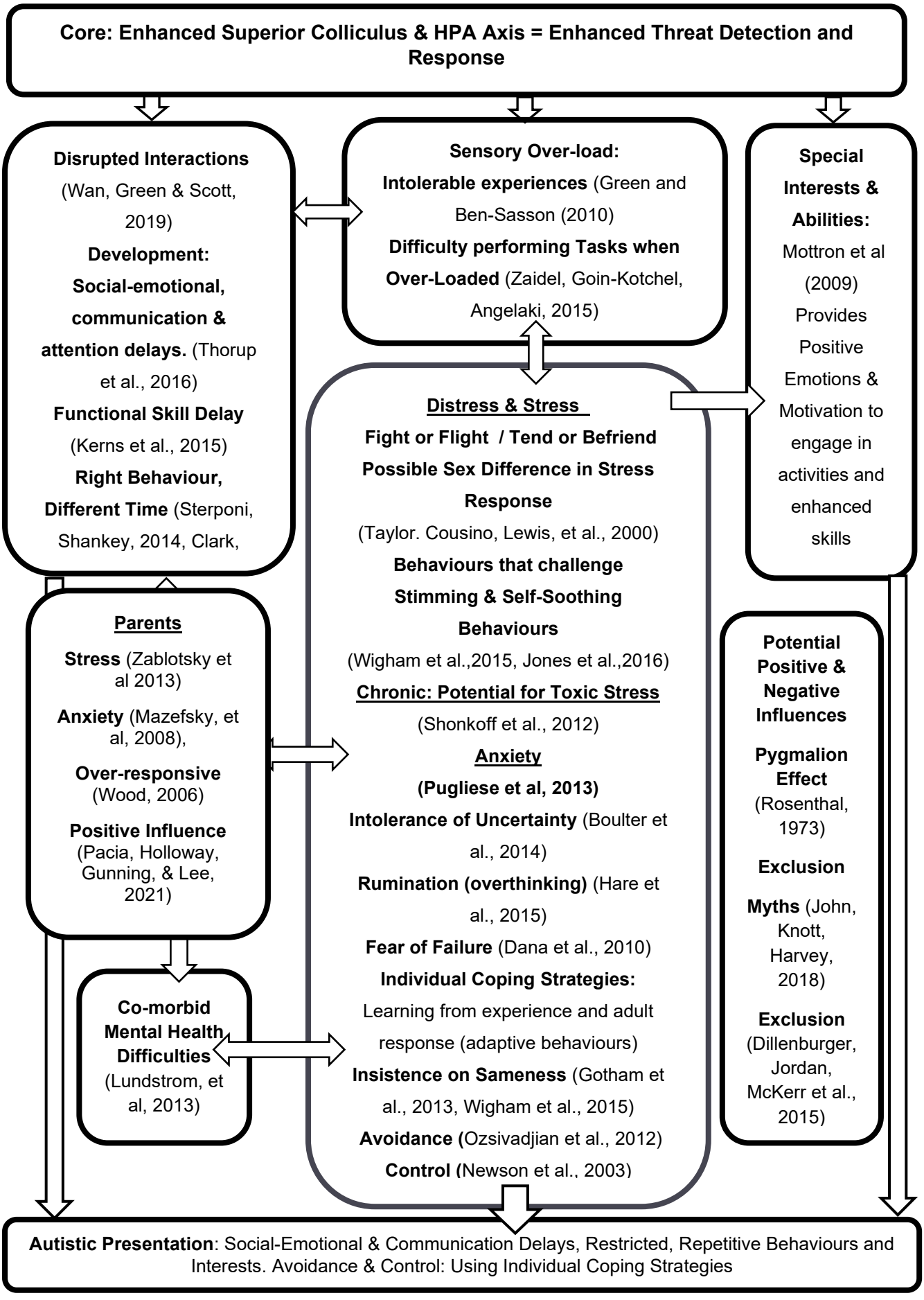
Importantly, these strands of literature do not operate in isolation but converge on a shared set of assumptions. First, they collectively challenge the primacy of individual pathology, instead situating development within dynamic systems of interaction. Second, they emphasise the centrality of relationships, environments, and meaning-making processes in shaping outcomes. Third, they highlight the limitations of narrowly defined outcome measures—such as symptom reduction—arguing instead for broader considerations of wellbeing, participation, and quality of life. This convergence reflects an emerging consensus that what matters is not simply whether autistic individuals approximate neurotypical norms, but whether they are able to live meaningful, fulfilling lives within supportive contexts.

Within this reframed landscape, Positive Psychology offers a particularly coherent and generative framework. Its focus on strengths, flourishing, wellbeing, and optimal functioning aligns closely with neurodiversity-informed perspectives and with the relational emphasis of contemporary interventions such as PACT. Rather than positioning support solely in terms of remediation or risk reduction, a Positive Psychology approach directs attention toward enhancing resilience, agency, positive identity development, and supportive environments. Crucially, it provides a conceptual bridge between individual experience and

contextual factors, allowing for a more holistic understanding of development that incorporates both challenges and capacities.

Thus, the integration of these bodies of work leads directly to the rationale for adopting a Positive Psychology lens in the present study. By synthesising insights from neurodiversity theory and interaction-focused intervention research, it becomes evident that a strengths-based, wellbeing-oriented approach is not merely an adjunct to autism research, but a necessary evolution of it. The focus of this work, therefore, is grounded in the proposition that supporting autistic individuals requires not only reducing barriers and enhancing communication, but also actively promoting the conditions under which they can thrive.

Figure 11. Autistic Development Theory: Factors Potentially Influencing Development



This chapter has described Autistic Development Theory and a complex systems framework to understand the factors that may influence autistic children's development., either positively or negatively. The framework enables an understanding of an individual's developmental trajectory and accounts for the wide range of behavioural presentations that may emerge. Within this framework, some behavioural presentations are deemed to be typical developmental transitions that occur at the correct developmental phase though may be chronologically out of place and not unique to autism. There are numerous possibilities for further research and potential changes to practice that potentially arise from ADT. These will be explored in the final discussion chapter of this thesis.

The Adapted Phenotype Theory, an Evolutionary Perspective and Autistic Development Theory challenge the current understanding of autism as a life-long disability of social interaction/communication and restricted repetitive interests. Combined, these theories provide a potential explanation of what systems are enhanced (SC/HPA axis), why they are enhanced (threat detection and reaction during environmental instability) and how autistic children's development may be influenced by various factors.

The complex systems framework that is provided in this chapter highlights the interrelatedness of the various factors and brings the opportunity to understand each child's unique presentation and to provide support and interventions to meet their needs effectively. The theories have also highlighted that autistic children are at greater risk of experiencing chronic or toxic stress. The potential short- and long-term damage from this may be buffered by a caregiver who is present and has the skills to support the child through their challenges and develop resilience. It is therefore important that practices that may decrease stress and anxiety and increase well-being are explored for autistic children and their families.

The novel theory has value as it offers an explanation of the heterogeneity of autism and provides choices of support and intervention at various stages. Whilst based on current evidence and understanding of child development, as a theory, it is not tested. This would be an important next step. A possible evaluation of the theory could be an in-depth exploration of a sample of autistic children and their development over time. A longitudinal study tracking children's development across time may lend no support to Autistic Development Theory (ADT), or support the efficacy of it. Until this is determined, the emphasis should be that ADT is a theoretical model that may serve to help the understanding of autistic children and inform support and interventions.

ADT suggests that disruptions in early infant-caregiver interactions contribute to socio-communication delays, interventions could focus on sensory regulation and guided social engagement from infancy. Helping infants regulate SC/HPA axis responses through

controlled sensory environments, reducing overstimulation and improving engagement. Interventions may encourage parental strategies that optimize gaze-following and attentional engagement to support social learning. Since atypical visual scanning patterns are observed early, structured visual interventions could enhance social attention and reduce the impact of SC hyperactivity. If parent-infant interactions shape later socio-communication development, caregiver training could play a crucial role in reducing developmental delays. Educating parents on how to recognise and manage sensory overstimulation could improve dyadic interactions.

By integrating these insights into early interventions, diagnostic frameworks, and caregiver support, ADT provides a developmentally informed approach to improving outcomes for autistic individuals.

A discipline of applied psychology is Positive Psychology (PP.), which focuses on understanding well-being and theories and practices to enhance well-being in adults and children. PP may offer theories and practices that may be beneficial to autistic children and their families. The next chapter considers PP theories and practices that may meet the needs that have been identified in this chapter and the previous chapter.

CHAPTER FOUR

POSITIVE PSYCHOLOGY INTERVENTIONS AND THE POTENTIAL VALUE FOR AUTISTIC CHILDREN

Introduction

This chapter will focus on Positive Psychology (PP.) and the theories and practices that may be beneficial for autistic children and their families to enhance well-being. The aim, building on the description of Autism Development Theory in the earlier chapter, is to view the child, their family and their context systemically and to develop an intervention for autistic children that can be delivered to them by their parents. This chapter will explore this alongside the reported benefits to individuals and their development and well-being. Initially, a brief review of current interventions and practices follows.

Treatments and Interventions for Autistic Children

Early theorists such as Kanner (1944) were practitioners and theorists seeking to understand the child and find ways to support the child's development and develop insight and guidance for other practitioners. Many interventions have since been developed to use with autistic children, families and others, either educationally or therapeutically. Some of these interventions focus on specific skill development, such as Lego Therapy (Owens, Granader, Humphrey, & Baron-Cohen, 2008), while others use a whole-child approach. This section will review interventions, their effectiveness and some associated controversies.

Well-being

There are examples of enquiry into what creates a good life that reaches back over centuries (Atkinson, 2013), as far back as ancient Greece (Frijters, Clark, Krekel, & Layard, 2019). There are various definitions of well-being, from different domains, such as social policy and psychology. The concept of what well-being is, and how it can be measured is an essential aspect of the work related to this thesis, and how any subsequent intervention is informed. Therefore, consideration needs to be taken regarding the theoretical underpinnings of the proposed intervention. The concept of ‘spaces of well-being’ will initially be discussed as it appears to dovetail with ADT.

Spaces of Well-being

Atkinson (2013) proposes that well-being should be understood as effects produced at specific times and places, rather than components that can be obtained as internalised, individual qualities. This perspective advocates for well-being to be framed as situated and

relational, enabling the gaps to be bridged between the subjective and objective, and the individual and the collective.

The 'spaces of well-being' approach propose interrelated spaces of resource mobilisation, capabilities, social integration, security and therapeutic process. With this model, Atkinson (2013) suggests that well-being depends on several situated and relational factors that can change over time. As habits form and routines are produced, well-being may become stable, only then is it meaningful to measure well-being over the medium term. This model shifts the focus of interventions away from the individual to a multifaceted focus:

> *'A shift is demanded away from how to enhance the resources for well-being centred on individual acquisition and towards attending to the social, material and spatially situated relationships through which individual and collective well-being are affected. As Haidt proposes, 'Happiness comes from the between'* (2006: 213)' (Atkinson, 2013, p. 142).

This approach is a significant shift from the component models, with well-being as an internal set of components that can be built and fed, to understanding well-being as flexible and context-related. McNulty and Fincham (2012) propose that well-being is determined by an interplay between a person's characteristics and the quality of their social environment.

It is usual to choose a theory or framework that provides the best fit for the researcher and the problem being addressed. The spaces of well-being approach fits exceptionally well with Autistic Development Theory. Within both, there is a recognition that an individual's lived experience will be context-dependent, and a complex interplay of factors will impact the well-being of the individual and the collective. Therefore, the spaces of well-being approach may be a guiding principle in which to inform the proposed programme. This said, it is not to teach parents a set of principles per se, instead, as an underlying ethos that sits behind the programme's content in its entirety.

Ospina et al. (2008) classified interventions as on a spectrum from behavioural to developmental, as shown in Table 1. Some interventions are aimed at developing specific areas of delay, such as communication (Pickles et al., 2016), while others are more holistic life-wide approaches, such as Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) (Butler, 2007).

Table 6. Ospina et al (2008) Classification of the Behavioural and Developmental Continuum of Interventions for Autism Included in the Review with corresponding Evaluation of Findings

Continuum	Intervention	Overview
	Applied Behavioural Analysis (12 Studies)	Effects of discrete trial learning inconsistent across studies; all compared to no treatment reported significant findings; often motor and functional outcomes had positive results; communication mainly negative; all cohort studies found significant results. Lovaas therapy compared to special education showed variable results between studies, and appeared to show effects in medium-term studies that didn't show in the long-term studies; in comparison to Developmental Individual-difference relationship intervention (DIR) or Integrative/Discrete trial with Treatment and Education of Autistic and related Communication Handicapped Children (TEACCH) there were no significant differences; 7 out of 8 studies reporting significant findings were not randomised controlled trials; 3 out of 4 randomised controlled trials reported no significant findings.
	Communication Focused Interventions (10 studies) Intervention: Computer Assisted Instruction; Picture Exchange	Statistically significant results and positive effects at the study level for 2 studies in emotional recognition; 1 study of close generalisation tasks; 1 study of attention; 1 study of verbal IQ and 1 study of motivation; all studies were randomised controlled and involved active intervention groups and no treatment; 3 studies found sign language to be beneficial in communication development.
	Contemporary ABA (10 studies) Intervention: Cognitive Behavioural Therapy; Discrete Trail Training; Pivotal Response Training; Incidental Teaching	Significant improvement following Cognitive Behaviour Therapy in social skills, behaviour management and parental mental health; limited and inconclusive evidence for various combinations of milieu teaching; pivotal response training, discrete trial training and incidental teaching; some evidence for benefits for communication and social interaction from pivotal response training.
	Developmental Approaches (12 studies)	No short-term difference between no treatment and Developmental Individual-difference Relationship-

Continuum	Intervention	Overview
	Intervention: Developmental Individual-difference Relationship-based Interventions; Imitative Interaction; Incidental Teaching; Milieu Therapy; More Than Words; Responsive Training; Scottish Centre Programme	based interventions in self-stimulating behaviour, aggression and social skills; no evidence of effect: a comparative study of two incidental teaching based approaches on social skills; 2 milieu based approaches in play behaviour and communication and responsive training and no treatment in parental attitude towards autistic, child aggression, externalising problems, depressive or anxiety symptoms. Positive results in cognitive abilities and course of autistic symptoms in comparison to milieu therapy and no treatment and milieu in comparison to Picture Exchange Communication in communication and play behaviour. More than Words showed positive results in vocabulary size and facilitative strategies compared to waiting list controls but not in behaviour, social skills parental stress or adaption. Compared to standard care, Response Training was found to be superior in the development of expressive language and reciprocal social communication; the Scottish Centre Programme showed positive results in social interaction, joint attention, imitation, daily living skills, motor skills and adaptive behaviour.
	Environmental Modification (1 study) Intervention: Work Placement	In 1 study of 44 cohorts, work placement compared to a waiting list prospective cohort study reported significant improvement in cognitive performance and non-vocational outcomes.
	Integrative Programmes (14 studies) Intervention: Discrete Trail Training + Floor Time or Pivotal Response Training; Lego Therapy; Social Skills Programme; TEACCH	Lego therapy was evaluated in 1 retrospective cohort study and found significant improvements in autistic symptoms and social skills; Social skills programmes were evaluated in 6 studies which found inconsistent outcomes with no identified pattern to explain these. TEACCH was evaluated in individual studies which consistently reported significant outcomes in areas including fine motor and gross motor skills, cognitive performance, communication, and adaptive social functioning. No studies evaluated long-term outcomes.

Continuum	Intervention	Overview
	Sensory Motor Interventions (15 studies) Intervention: Auditory Integration Training (5); Exercise; Restricted Environmental Stimulation Therapy (2); Sensory Integration (5)	15 studies evaluated sensory-motor interventions, evaluating various modalities: exercise; restricted environmental stimulation therapy; sensory integration and auditory integration training. 6 studies of sensory integration found significant results for stereotypic behaviours; off-task behaviours and aversion to touch, in comparison to controls of no treatment. The researchers note that it is not known how sensory integration compares to other interventions. The outcomes for communication were found to be contradictory, and no effect was found on intellectual functioning. 2 Creative dance studies showed significant social gains, as did horse riding. Restricted environmental stimulation therapy was inconclusive.
	Social Skills Development Interventions (6 studies) Social Stories	Trials of Social Stories ™ assessed the effect on social interaction outcomes in the short term. 5 out of 6 found statistically significant results. No studies comparing Social Stories ™ to other interventions.

As Table 1 shows, some interventions are aimed at developing specific areas of delay, such as communication (Pickles et al., 2016), while others are more holistic life-wide approaches, such as Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH) (Butler, 2007). The most evaluated intervention is Applied Behavioural Analysis (ABA), which includes traditional and contemporary ABA (Ospina et al., 2008). Even though the dominant approaches in the UK are speech and language therapy, visual schedules (TEACCH) and ABA (Denne, Hastings, & Hughes, 2018), these are antithetical to positive psychology. For this reason, the focus of this review will be on NAS Earlybird and Cygnet programmes.

NAS Earlybird

The NAS Earlybird programme is a psychoeducational group-based programme for parents developed in the United Kingdom (Zakirova-Engstrand et al., 2023). The programme is three months of post-diagnosis support for parents of children under five years old. The aim is to enhance autistic children's social and communication skills and reduce problematic behaviour through parental education about autism and enhancing confidence and competence in parenting their autistic child. Parents participate in group sessions, led by trained facilitators and peer support is encouraged. Facilitators also undertake home visits to observe parent-child interactions and video these for feedback during group sessions (Zakirova-Engstrand et al., 2023). Earlybird evaluation studies have reported that both parents and facilitators held positive views of the programme, with pre and post-outcome measures showing positive changes. The researchers reported that recruitment of participants was challenging and strategies to enhance this is necessary for the future (Palmer et al., 2019). It could be postulated that recruitment was a challenge due to the length of the programme, which is a significant expectation for families who already have many constraints on their resources.

Cygnet

Cygnet is a programme for parents and carers of autistic children aged five to eighteen, presented to groups over six three-hour sessions aiming to work towards behaviour management of autistic children. Cygnet aims to increase parents understanding of autism, how autistic children experience the world, what leads to particular behaviours and help parents with strategies to use with their children to support behaviour, play and communication (Stuttard et al., 2016).

The parent-mediated NAS Earlybird and Cygnet are both psycho-educational group-based interventions designed to support parental understanding of autism and the use of strategies to support the development and behaviour of their children. The evaluations of both are limited and therefore evidence for efficacy is limited. However, both have reported outcomes of parental positive experiences (Palmer et al., 2019; Stuttard et al., 2016). In contrast, TEACCH and ABA appear to have the potential for closer collaboration with families and educators albeit administered by a therapist/teacher.

Both NAS Earlybird and Cygnet were developed many years ago when the prevalence of autism was lower than it is currently. This increase in children identified as autistic leads to more families with a need for support from local authorities. The uptake of NAS Earlybird and Cygnet by local authorities or other organisations may be impacted by the intense resources required to provide these programmes to parents and lead to

prohibitive costs. Additionally, the extensive time commitment expected from parents may also lead to parents not being able to access them due to work and/or family commitments.

Parents and children may benefit from parent-mediated interventions and psycho-educational programmes. However, the current constraints of parental time pressure and local authority budgetary pressures may inform programme planners that interventions should be as time-limited as possible.

Positive Psychology: An Evolving Discipline of Research and Practice

Introduction

Positive psychology (PP) is the science of positive individual traits, positive subjective experience and positive institutions. The overarching aim is to improve people's quality of life and enable individuals to achieve higher levels of wellbeing (Seligman & Csikszentmihalyi, 2000). Theoretical developments within the field have led to evidence-based practices which are said to increase wellbeing (Bolier et al., 2013). This chapter will discuss positive psychology, the three distinct proposed waves and the interventions that have been found to enhance well-being. Positive psychological interventions will be reviewed and discussed in relation to applying practices to use with autistic individuals and their families to enhance well-being.

Traditionally, Mental Health services have treated mental illness, focusing on the deficit-driven medical model of illness and disease (Slade, 2010). Recent years have seen the prominence of PP increase and begin to influence thinking and practice within traditional Mental Health services. Slade (2010) welcomed the contributions that PP was bringing to Mental Health and suggested integrating wellbeing practices into mental health provision to encourage mental wellness rather than focus on treating conditions. These changes in thinking reflect the shifts within the field of disability and social care, moving towards the social-ecological model of disability. The social-ecological model recognises there is often a mismatch between the person's needs and their environment, leading to barriers and limitations for people who live with differences (Shogren, 2014). The social-ecological model focuses on an individual with a strength development approach and is aligned with the ethos of PP and the interventions from the field. A different approach to how people with needs are supported and enabled has emerged with the implementation of personalisation and strengths-based support. This new approach moves away from programmes which offer a one size fits all approach to a particular condition or difference. Personalised support aims to use community resources and the role of the professional is one of a partner who supports a

self- determined person to plan and create a life that is meaningful within their natural environment and community (Buntinx, 2014). Zager (2014) suggests that PP has the potential to provide good outcomes for autistic people. Therefore, applying PP approaches to enhance the lives of autistic children, young people and their families sits with national and global policy and the call for preventative and person-centred support. The previous chapter highlighted the vulnerability of autistic people for developing co-morbid mental health problems. Positive psychology approaches may provide opportunity for autistic children and their families to build their resilience and well-being and provide a buffer against mental illness. By focusing on what autistic children can do rather than what they struggle with, PP may provide a hopeful, empowering framework that supports both individual flourishing and broader social inclusion.

Positive psychology is an evolving discipline and is reported to have three distinct waves that will now be discussed.

First Wave Positive Psychology

The study of human well-being and happiness is not new. Seligman and Csikszentmihalyi (2000) noted that the main focus of psychology had been on pathology. To redress the balance, they called for PP to be a distinct area of research and practice with a focus on what is right and what is essential for human flourishing. They outlined a framework for the science of positive psychology and suggested that the future will lead to the science and profession of PP understanding and building the factors that enable societies, communities and individuals to flourish. They suggested that wellbeing is created by having:

- Hope and optimism for the future
- Satisfaction and contentment with the past
- Flow and happiness in the present.

Since its inception, PP has provided opportunities for diverse topics to come into an emerging field. There was a rise in the development of new theories (Lopez, Gallagher, 2009) and self-report scales measuring strengths and elements associated with well-being, such as life satisfaction, hope, optimism, meaning and flow (Diner, 2009). Positive Psychology Interventions (PPI.'s) were created, aiming to support the development of well-being through the use of evidence-based exercises (Parks, Acacia. Schueller, 2014).

For example, an online study evaluated the effectiveness of six exercises (Seligman, Steen, Park, & Peterson, 2005). Some exercises had a lasting impact on happiness and it was proposed that PPI.'s may be beneficial to use alongside traditional interventions.

Happiness was considered a difficult concept to focus on scientifically, so they proposed that PP should focus attention on activities that related to the concepts of a meaningful, pleasant and engaged life. In a later review of interventions, Parks and Schueller (Parks, Schueller, 2014) identified constructs that PPI.'s had focused on and found that some were more extensively researched than others. The established areas were gratitude, forgiveness, savouring, strengths, meaning and empathy. Emerging areas were those of creativity, patience, courage, humour, flow and wisdom. The review found that PPI.'s were being applied in a variety of settings by a range of practitioners and had the potential to be applied in other settings and with different populations, including children and people experiencing mental health problems. Some interventions were adapted to use with specific groups, such as people diagnosed with depression (Carr & Finnegan, 2014; Learned, York, Seligman, Rashid, & Parks, 2006; Shoshani & Steinmetz, 2013) and schizophrenia (Meyer, Johnson, Parks, Iwanski, & Penn, 2012).

Positive psychology has been subject to critique, McNulty and Fincham (2012) state that the key assumption that psychological traits are either positive or negative is questionable, suggesting that PP should look beyond positive or negative and consider the context in which they are operating. An example is forgiveness in an abusive relationship, which has the potential to lead to harm to the individual. In this context being un-forgiving may instead lead to enhanced well-being and mitigate risk to the individual.

The initial focus of positive psychology sent a message that positive was desirable, and negative was not (Ivtzan, Lomas, Hefferon, & Worth, 2016). This occurred despite Seligman's earlier warning about how realism may be created by pessimism and in some circumstances, optimism can be detrimental. For example, being overly optimistic may prevent people from seeing the harsh realities of situations. The emergence of PP has led to interventions that are popular with coaches and the media. Diner (2009) suggests that the desire to use these avenues to share the PP message could potentially lead the field to offer overly basic solutions (Diner, 2009). The aim for PP to provide evidence-based practices has led to experimentally supported exercises that appear to provide positive outcomes, for example, enhancing gratitude and optimism (Froh et al., 2014; Santos et al., 2013; Seligman et al., 2005), that out of context, may be considered by recipients as simplistic and far removed from lived experience.

Second Wave Positive Psychology

Positive psychology is said to have a 'second wave' (Ivtzan. et al 2016) with the positives and negatives of life being acknowledged. The term 'second wave' was used by Wong (2011) to describe the development of this new movement within the field. The second wave

or PP2.0 (Wong, 2015) is described as an umbrella term which represents the five themes which distinguish PP2.0 from the original PP. These defining themes are:

1. Focusing on positive emotions, traits and institutions is indefensible, positive and negative are related dynamically and Wong (2015) explained that if PP1.0 was represented by a smiley face, PP2.0 would be represented by the Yin and Yang symbol.
2. Long-term well-being is to be achieved if the 'dark side' of life is embraced and transformed. There is a need to confront the dark side and to achieve this there needs to be new, innovative research and interventions which are informed by existential insights.
3. There is a need to cultivate humanistic values and global virtues to help people to become more moral and good, in kinder, more gentle societies.
4. The assumption that concepts and research from American PP can be accepted as universal is inappropriate with the acknowledgement that cultural differences may lead to different routes to well-being.
5. There is a favour for qualitative research and shared knowledge from the humanities rather than the focus on quantitative empirical research.

Wong (2011) suggests four 'pillars' of the good life; meaning, virtue, resilience and well-being. The following section will discuss the key pillars of PP2.0 meaning, well-being, virtue and resilience.

Third-Wave Positive Psychology

Third-wave positive psychology (PP 3.0) broadens beyond the earlier waves by acknowledging the systemic, cultural, and contextual influences that may impact well-being. PP 3.0 emphasizes equity, diversity, and collective well-being, recognising that well-being is influenced by social structures, cultural backgrounds, and systemic factors (Lomas, Waters, Williams, Oades, & Kern, 2021). This shift aligns with the growing awareness that mental health and flourishing cannot be separated from social justice, environmental sustainability, and global well-being.

In contrast to earlier waves that sometimes promoted a universal model of happiness, PP 3.0 acknowledges that well-being is deeply influenced by individual differences and socio-cultural contexts. The third wave of positive psychology also highlights the importance of systemic interventions and, therefore, family interventions needs to be considered from this perspective. It moves beyond self-help approaches to focus on

organizational, educational, and societal transformation (Lomas et al., 2020). Research suggests that interventions aligned with PP 3.0—such as community-based resilience programs, workplace well-being policies, and culturally tailored interventions are more sustainable and impactful than purely individual-focused strategies (Ivtzan et al., 2016). Moving forward, PP 3.0 encourages interdisciplinary collaboration, drawing from fields such as sociology, environmental science, and public health to create holistic models of well-being. This evolving framework represents a paradigm shift toward more ethically conscious, socially responsible, and globally relevant positive psychology.

What 'Waves' This Research Relates To

To create a comprehensive, effective, and person-centred intervention for autistic children, it is key to draw on all three waves of positive psychology. Each wave contributes unique insights that, when combined, offer a more holistic, strengths-based, and inclusive approach. By integrating elements from the first, second, and third waves of positive psychology, interventions may enhance well-being and resilience but also acknowledge challenges, diversity, and environmental influences that shape the autistic lived-experience.

The first wave of positive psychology (Seligman & Csikszentmihalyi, 2000) highlights that happiness, strengths, and positive emotions are fundamental to enhancing quality of life. For autistic children, this could involve gratitude practices, engagement in special interests, and fostering positive relationships. Strength-based interventions may help autistic children build confidence in their abilities, focusing on what they can do rather than what they have difficulty with.

The second wave of positive psychology (Wong, 2011) recognises that well-being is not just about positive experiences but also about meaningfully navigating adversity. This is particularly relevant for autism interventions, as autistic individuals often face sensory challenges and a mismatch between the individual and the context or environment. Integrating this perspective allows interventions to validate and work through difficulties by creating strategies to avoid or manage difficulties.

The third wave of positive psychology (Lomas et al., 2020) expands beyond the individual to societal and systemic well-being, advocating for neurodiversity, inclusion, and social justice. This is critical for autism interventions, as many challenges autistic individuals face are environmental. By utilising third-wave principles, interventions may focus on creating supportive environments that foster true inclusion rather than requiring autistic individuals to conform to neurotypical norms. By integrating all three waves, a multi-layered approach may ensure that interventions are person-centred, strengths-based and adaptive to real-world challenges.

Positive Psychology Interventions

Positive Psychology Interventions (PPI.'s) are structured activities or sets of practices that have been designed to enhance well-being, evoke positive emotions, and develop psychological resilience (Sin & Lyubomirsky, 2009). PPI.s emphasise building strengths, fostering meaning, and cultivating positive relationships. PPI.s can take various forms, for example, undertaking gratitude exercises (Emmons & McCullough, 2003) or practising mindfulness and self-compassion (Neff, 2011).

Positive psychology interventions were defined as those with the goal of enhanced well-being being achieved through pathways that are consistent with positive psychology theory. Using this definition, a meta-analysis of 347 positive psychology interventions found a small to medium effect on well-being and strengths and reducing depression, anxiety and stress (Carr et al., 2021). These findings reflect those of a previous analysis that found positive psychology interventions can improve subjective well-being and psychological well-being, as well as help to reduce depressive symptoms (Bolier et al., 2013). A large meta-analysis of 72,000 participants from 41 countries found that well-being, strengths, depression, anxiety and stress were all positively impacted. The reported gains were maintained at three months follow-up (Carr et al., 2021). Originally, PPI.'s have been delivered in person or using telehealth methods. The arrival of the global COVID-19 pandemic led to several measures to reduce the spread of the virus, including stay-at-home rules and social distancing. It has been noted as a result of that experience that PPI. delivery could be through digital mediums. There is also a suggestion that the viral spread reduction measures may increase loneliness and this may be a focus of interventions in the future (Parks & Boucher, 2020).

Waters (2020) conducted a randomised wait-list control study involving 300 families across six countries. The research aimed to assess the effectiveness of two specific PPI.s designed to promote family well-being: The Strengths Family Contract Intervention involved goal-setting, identifying individual family members' strengths, and recognising strengths in others within the family unit. The second was the Strong Ancestry-Strong Family Intervention, which encouraged families to share stories highlighting the strengths and resilience of ancestors and relatives, concluding in the creation of a strengths-based family tree. The study found that those participating in either of the PPI.'s experienced significant increases in happiness levels compared to their pre-intervention assessments and relative to the control group. Notably, there was no significant difference in effectiveness between the two interventions, suggesting that both approaches are equally beneficial in enhancing family happiness. This study illustrates the potential of PPI.'s to enhance family happiness

by utilising strengths-based approaches and storytelling to build resilience and positive family dynamics. It highlights the importance of focusing on positive practices within the family system to promote collective well-being.

Positive Psychology & Autism

Before discussing the applicability of positive psychology (PP.) in interventions for autistic children and their families, it is essential to clarify key terminology. The term "strengths-based" has become widely used, and researchers and practitioners should clearly define the meaning in their interventions (Niemiec & Pearce, 2021).

In autism research, strengths are increasingly recognised as integral to understanding and supporting autistic individuals. Autistic strengths are typically categorised into several domains, these are:

- Perceptual Strengths: Enhanced sensory perception, for example, acute attention to detail and heightened sensitivity to environmental stimuli.
- Cognitive Strengths: Enhanced abilities in pattern recognition, systematic information processing and logical reasoning.
- Expertise: Deep knowledge and intense focus on specific subjects or interests often lead to high levels of proficiency.
- Character Strengths: Traits like honesty, loyalty, and determination, contribute to personal integrity and reliability.(Cherewick & Matergia, 2024).

The Character Strengths and Virtues (CSV) framework identifies 24 universal character strengths categorised under six core virtues, providing a strengths-based approach to well-being and flourishing (Niemiec & Pearce, 2021). While this framework is highly regarded and beneficial for well-being, research suggests that character strengths in children are not yet stable. A study examining a diverse sample of 2,467 children aged 9 to 19 found that older adolescents demonstrated a greater differentiation of character strengths, indicating increased complexity in character development with age (Shubert, Wray-Lake, Syvertsen, & Metzger, 2019). These findings emphasize the importance of considering developmental stages when fostering character strengths. Given that character strengths evolve through childhood and adolescence, they will not be included as a practical application in the proposed intervention.

The strengths-based model advocates for identifying and nurturing individual abilities rather than focusing solely on deficits. By emphasizing strengths, this approach aims to foster self-determination and personal growth. For instance, behaviours traditionally viewed

as challenges, such as intense focus or adherence to routines, can be reframed as persistence and attention to detail, offering valuable assets in various contexts (Fung, 2021).

In this thesis, ‘strengths’ refers to abilities, talents, interests, and attributes. In the field of PP, however, the term specifically denotes "character strengths."

Zager (2014) suggests that PP. can provide good outcomes for autistic people, and interventions may be aligned with other interventions. Despite the shift in approach, it is reported that few studies apply positive psychology approaches to the field of disability (Niemiec, Shogren, & Wehmeyer, 2017).

There is little PP. research into positive psychology interventions and autism. A small-scale study of 3 families (Singh et al., 2014) developed an eight-week programme for mothers. They taught mothers to use positive behavioural support (though not grounded in positive psychology) with their autistic adolescent children, alongside mindfulness meditations for themselves. The programme was developed as the researchers found most parents were advised to use applied behaviour analysis (ABA) with their children, who found it time-consuming and stressful. The programme aimed to provide parents with training in positive behavioural support to enhance their children's development and decrease aggressive and destructive behaviours. The positive behaviour approach was chosen as there is no need for highly technical support plans and time-consuming and reportedly stressful, A.B.A. They found mother's stress decreased, as did the presentation of behaviours that challenge others and aggression from the children (Singh et al., 2014). Whilst this is a small-scale study, it indicates the need for interventions to include family members and offer a holistic, life-wide approach. It is not clear whether the change in parenting style or the decrease in mothers' stress created a positive change in the children's behaviour or whether it was a result of a combination of the two. An alternative contributory factor to these findings could be that as all participating families had previously used A.B.A., the children may have found the process equally as stressful as their mothers. Presenting aggressive and destructive behaviours may have been the attempts to communicate this stress using the only strategies they had at the time. If this is the case, removing A.B.A. may have automatically led to decreased stress in both parent and child. However, the study has shown that there may be potential to use positive psychology approaches to enhance family and child well-being. While there is barely any research on PP. and autism, there have been changes to mental health and social care practices that lend further support to utilising PP., a discussion of which follows.

Traditionally, Mental Health services have treated mental illness, focusing on the deficit-driven medical model of illness and disease (Slade, 2010). Recent years have seen

PP. increase and begin to influence thinking and practice within traditional Mental Health services. Slade (2010) welcomed PP.'s potential contributions to Mental Health and suggested integrating well-being practices into mental health provision to encourage mental wellness rather than focus solely on treating conditions. Further to this, the COVID-19 pandemic led to the suggestion that PP. has much to offer in times of intense crisis, to boost mental health and potentially shield from mental illness (Waters et al., 2022). This review highlights that PP. may have much to offer autistic children and their families.

These changes in thinking reflect the shifts within disability and social care, moving towards the social-ecological model of disability. The social-ecological model for interventions recognises that there is a complex interplay between individuals and environment-specific variables, and these frameworks have been applied to disability contexts (Walker et al., 2011), recognising there may be a mismatch between the persons' needs and their environment. The social-ecological model focuses on an individual with a strength-development approach and is aligned with PP.'s ethos and interventions. Different approaches to how people with needs are supported and enabled have emerged with personalisation and strengths-based support in social care. This new approach moves away from programmes which offer a one-size-fits-all approach to a particular condition or difference. Personalised support aims to use community resources, and the role of the professional is one of a partner who supports a self-determined person to plan and create a meaningful life within their natural environment and community (Buntinx, 2014).

It has been suggested that not all activities will benefit every individual (Lyubomirsky, Sheldon, & Schkade, 2005). The 'fit' of an activity to an individual may depend on several factors, such as; individual characteristics, strengths, needs, resources and motivations (Lyubomirsky et al., 2005). In a study that considered the characteristics of happiness seekers, the researchers found two subsets of people, distressed and non-distressed. They concluded that the approach of one size fits all to intervention research should be replaced with more nuanced models that evaluate the potential fit of an activity for an individual (Parks, Della Porta, Pierce, Zilca, & Lyubomirsky, 2012). Further to this three conceptual models have been offered; the eudaimonic activity model, the hedonic adaption prevention model and the positive activity model (Sheldon & Lyubomirsky, 2021). The eudaimonic (seeking happiness through meaning and purpose) activity model proposes that by engaging in eudaimonic, growth fostering and intentional behaviours, basic psychological needs are met which raises well-being. The hedonic adaption prevention model proposes that hedonic adaption to a life change, for example, getting used to a new car, is not inevitable. How an individual interacts and has positive experiences of the life change may lead to continued higher well-being. The final model, the positive activity model identifies moderating and

mediating factors. Moderating factors have three categories; those relevant to the activity, the person and the intersection between the two, which is said to be person activity fit.

The issue of personal activity fit highlights that when developing a programme for parents, it will be important to provide a range of activities for parents to choose from. This need is furthered by the proposed programme aiming to enhance the whole family's well-being. Potentially, there will be a diverse range of individual characteristics, strengths, needs and resources. Given this, it may be most helpful to teach parents the concepts behind interventions, with some example exercises. The programme could encourage parents to use the concepts to create activities that are suited to their family as a whole and members individually. The following discussion considers the PP. theories and interventions that may be included in the programme or adapted for the programme and initially focuses on P.E.R.M.A. Theory.

P.E.R.M.A. Theory: Components for Flourishing

Seligman (2011) proposed that well-being is supported by five components, for which he uses the acronym 'P.E.R.M.A.', to represent the components of Positive Emotion, Engagement, Relationships, Meaning and Accomplishment. Seligman believes that there is room for people to enhance their well-being and flourish. This component model considers that well-being may be acquired, and interventions may enable people to develop these components that may in turn lead to flourishing. The five components are described as the building blocks of well-being that enable flourishing (Seligman, 2018), P.E.R.M.A. may be a helpful framework for parents to understand the components that they can build on to enable themselves and their children to flourish and would be a useful tool to build into an intervention. Each element is briefly outlined below:

Positive Emotions

Increasing positive emotions is suggested to support well-being. Positive emotions related to the past may be increased through gratitude, in the present by using mindfulness and savouring, and in the future by being hopeful and optimistic. The ‘Broaden and Build’ model reports a set of positive emotions, that when experienced, expand and build the transitory thought-action repertoire. The effect of this is that a person’s intellectual, physical and social resources are developed from their pre-existing state (Fredrickson, 1998). Broaden and Build theory (Fredrickson, 2003) explains that positive emotions may limit the impact of negative emotions. Finding ways to cultivate positive emotions is proposed to lead to increased health and well-being (Fredrickson, 2003). It has also been reported that positive

emotions may buffer against the emotional states characteristic of psychopathologies (Garland et al., 2010). It has been noted that positive emotions can co-exist with negative ones, but engaging strategies to increase joy and love can foster resilient coping (Waters et al., 2021). The complexity of challenges that autistic children may face is likely to lead to these mixed emotions and encouraging autistic children to experience higher levels of positive emotions in their daily lives, may help to increase well-being and resilience.

Further studies measuring biological responses to stressors found that experiencing positive emotions could undo the effect of negative emotions (Cohn & Fredrickson, 2009). A month-long study required participants to find a positive meaning in their best, worst and ordinary experiences. Compared to controls, the participants in the experimental group showed an increase in their resilience. These outcomes can lead us to assume that people may develop resilience by searching for and identifying positive meaning in everyday life. A further study, focusing on the Broaden and Build theory's build hypothesis, taught participants meditative practices, which they used for three weeks (Cohn & Fredrickson, 2009). Participants reported higher levels of positive emotions daily in comparison to controls and after the eight-week intervention, there were increases in wellness, agency, savouring and the reported quality of relationships. The researchers suggested that meditation practice increased the levels of positive emotion being experienced, leading to participants assessing their lives to be more satisfying and fulfilling.

A similar long-term study requiring participants to undertake loving-kindness meditation found that perceived social connections build positive emotions and physical health, suggesting that these are mutually influencing and operate in an upward spiral of positive affect (Kok et al., 2013). A recent study found that training adults in mindfulness meditation and loving-kindness meditation reported lower variability in social connectedness during the intervention (Don, Van Cappellen, & Fredrickson, 2022), highlighting the usefulness of building positive emotions for well-being and social connections. Another area of research and practice in PP. that may have relevance to autistic children and their families related to positive emotions is hope and optimism.

Hope Theory proposes that hope is the perceived ability to develop goals for the future and create pathways to achieve those goals (Snyder, 2002). Further to this is the proposal that purposeful actions are goal-focused (Buchanan, Lopez, 2014). Two types of thinking are involved as components of hope, pathway and agency. Pathway thinking is the ability to work out how goals will be achieved and generate a route to achieving them. Agency is the perception of the ability to achieve them (Snyder, 2002). Hope Theory suggests that pathways and goal-directed thinking begin to develop from birth, and from as

young as two to three years old hopeful thoughts begin to occur. Hope Theory suggests that children develop pathway and agency thinking through experiential learning from life experiences and parents, throughout childhood. Children learn to overcome barriers to goals from their parents, which sets the scene for the child's hopeful thinking in the future. It is also suggested that it is relatively fixed and stable over time and in development (Buchanan, Lopez, 2014).

There are said to be various benefits to having hopeful thinking. Buchanan and Lopez describe how hope is linked to academic success, lower levels of anxiety, better recovery from illness and fewer psychological problems than people with lower levels of hope (Buchanan, Lopez, 2014).

A study with adolescents with and without learning disabilities (Shogren, 2014), found that hope, optimism, locus of control and self-determination were correlated and hope and optimism were predictors of life satisfaction (Shogren, 2014). The hope of students with learning difficulties and peers who were high, mid and low achievers academically, was measured (Lackaye, Margalit, Ziv, & Ziman, 2006). Findings showed no differences in hope between the low achievers and the learning disability group. They showed lower levels of achievement, academic self-efficacy and positive mood than the high and mid-achievers. These findings suggest that hope is important, not purely for life satisfaction, but also for self-efficacy and attainment in life. A different study aimed to increase life satisfaction and hope in mothers who had autistic children. The study with 27 mothers of autistic children, found that participating in an eight-week positive parenting training course led to mother's hope and life satisfaction increasing significantly (Omid et al., 2018). A recent study found that adults with higher dispositional hope can positively influence resilience, subjective well-being and psychological health (Yıldırım & Arslan, 2022).

As part of the development and research into hope, is the development of the scales and measures. The Miller Hope Scale is a 40-item Likert response scale (Miller, 1986), measuring satisfaction with life, self and others, avoidance of threats to hope and anticipation for the future (Miller, 1986). Snyder (1991, 1997, 2009, Buchanan, Lopez, 2014) also developed several scales including the State Hope Scale (Snyder et al., 1996, Buchanan, Lopez, 2014) that also assessed goal-directed thinking. Further to this, Shorey et al. (Shorey et al., 2009, Buchanan, Lopez, 2014) developed the Revised Snyder Hope Scale, which included agency, pathway and goal-directed thinking. When evaluating interventions to increase hope, suitable measures are essential, and the State Hope Scale and the Revised Snyder Hope Scale are reported to have high internal consistency.

Optimism is a similar concept to hope and is proposed to be the expectation that good things will happen, while pessimism expects that bad things are likely to happen (Carver, Scheier, Miller, Fulford, 2009). In the following section, interventions that focus on hope and optimism will be discussed.

Hope & Optimism Interventions

Hope appears to be important for attainment and well-being, and a hope intervention may be included in the proposed intervention components. The complex intervention framework acknowledges that components may be developed or adapted from existing interventions, it is then worth consideration of existing hope and optimism interventions.

A self-management programme, 'Help to Overcome Problems Effectively', has been developed through positive psychology and cognitive behavioural research and therapy (Turner & Martin, 2017). The HOPE programme for cancer survivors is a six-week group-based self-management programme combining psychoeducation, cognitive behavioural skills practice, discussion, goal setting and reviewing, and expressing gratitude. The programme aims to build existing strengths and resilience (Turner & Martin, 2017). The programme has been evaluated with various groups, including parents of autistic children, and these participants showed the most significant increases in hope (Turner & Martin, 2017). One hundred and eight parents of autistic children participated, and the findings showed significant improvements in parents, depression, anxiety, well-being, gratitude and hope. (Martin, Clyne, Pearce, & Turner, 2019). These findings highlight that an essential aspect of an intervention for families of autistic children would be to attempt to increase hope as a means to improve parental well-being as has been found in the HOPE programme (Martin et al., 2019). Alongside hope, optimism has been taught to children using a variety of methods, in schools, or via parents.

Seligman (2007) offers parents a model to use with themselves and their children to change automatic pessimistic thinking. In his book 'The Optimistic Child', he offers the 'A.B.C.' (Adversity, Belief, Consequences) model, identifies pessimism and uncovers limiting beliefs. The next stage of the process is to learn an optimistic explanatory style and finally disputing and de-catastrophising. The model is based on the PENN. Resilience Programme (P.R.P.), which was developed for use in schools with children and had a strong empirical base (Seligman, 2007). The P.R.P. is based on Beck's Cognitive Theory and the A.B.C. model of Ellis (Bastounis, Callaghan, Banerjee, & Michail, 2016). A core element is changing the explanatory style of both parents and children from pessimistic to optimistic. Seligman suggests that there are three elements to explanatory style; these are Permanence; Pervasiveness and Personal. An analysis of 17 controlled evaluations of the P.R.P. found

that participants post-intervention and both follow-up assessments, reported fewer depressive symptoms compared to no intervention controls (Brunwasser, Gillham, & Kim, 2009). This is indicative that the P.R.P. may be a reliable intervention to reduce depressive symptoms.

While Seligman (2007) reports positive outcomes for school-based interventions quantitatively, a UK study trialled two interventions in 16 schools in Wolverhampton using a qualitative approach. The study used the Penn Resilience Programme (PRP) in Secondary schools and the 'Stop, Understand and Move On' programme in Primary schools, and analysed qualitative data from pupils and staff (Royle, 2015). The author reported an improvement in attitudes and behaviour, with improvements in responses to situations. It was also reported that pupils' relationships with each other and with staff improved. However, recommendations were that programme adaptability in response to the needs of the school is key and this is more difficult with the PRP as it is procedural in nature. This recommendation fits with the person-activity-fit findings (Lyubomirsky, Sheldon, & Schkade, 2005). A follow-up review (Royle, 2017) integrated and framed the programme activities through the capability approach, which provides a framework for assessing resilience interventions. The review also considered the construct of identity capital and an over-arching lens as to whether the Wolverhampton interventions were part of a *'wider phenomena of therapeutic governance*' (Royle, 2017, p. 54). Therapeutic governance is where there is a focus on social risk management for people who may be vulnerable to psychological and social dysfunction. Royle (2017) concludes that at a micro level, the programmes superficially enable some pupils to find a way to effective education, by increasing agency, accessing social capital and the skills to capitalise the self and identity capital to aspire to a different life.

However, at a macro level, it cannot be assumed that these types of interventions that develop skills to cope with emotions and provide coping strategies are effective in the face of societal limitations, such as race and economic issues. Royle (2017) proposes that school-based resilience and well-being programmes are not a solution to mental health issues and that schools should work with the community to engage with issues of society through the existing curriculum. Taking this into account, it could be proposed that engagement with children's wider support network would be valuable to enable and support change. Another school programme that focused on optimism that has included both school and parents has reported interesting outcomes and follows.

The Aussie Optimism Program (AOP) (Robers et al., 2018) had three in-school conditions;

- Teachers trained in the programme group which included 20 schools
- Teachers trained *and* supported by ongoing coaching, which included 22 schools
- 21 schools were in the usual care control conditions

The programme also provided a booklet for parents in the second half of grade 7 with advice on how to support the use of the child's skills in the home environment, and information on the 10 modules being taught in school. Parents were provided with log books to return.

Children were assessed before the intervention at the beginning of Grade 6 (aged 11 – 12 years), and three post-intervention assessments at the end of Grades 6, 7 and 8. The study included a child-reported Strengths and Difficulties Questionnaire and the Diagnostic Interview for Children and Adolescents, to assess depressive and anxiety disorders. Parent-reported Strengths and Difficulties Questionnaires were also used. The programme was delivered over two years, with the first year providing Social Life Skills modules, and the second year, Optimistic Thinking Skills, and a parent self-directed family programme in the second half of the second year. Children who had teachers in the training and coaching group had significant increases in pro-social behaviour, between pre-test 1 and post-test at the end of Grade 6, that were maintained in the Grade 7 post-test. This trend was not found in the teacher-trained cohort or the usual care condition. Additionally, they reported similar findings at Grade 7 for suicidal ideation, with decreases in the incidence in the training and coaching cohort, and not in the other two groups. The findings found that the teacher-trained condition was *'ineffectual at some points and counterproductive at others'* (Robers et al., 2018, p. 1).

These findings led the researchers to suggest that teacher training alone is not enough to implement mental health programmes. However, the programmes could be effective when the teachers have ongoing coaching and support. The findings that the programme was at times, counterproductive, raise concern regarding the delivery of programmes in schools. It is not clear why this was the case and warrants further investigation.

The family programme did not provide clear outcomes in the study, with a low return of log books. The researchers reported that parents appear to have developed an enhanced ability to navigate the changes with their children, from dealing with puberty and secondary school transition. The researchers suggest that future programmes should include workshops and role-plays that may be beneficial (Robers, et al., 2018).

The Wolverhampton study (Royle, 2017) and the AOP are relatively recent, and their findings do seem to lead to questions regarding the implementation of optimism

interventions in schools per se. These studies appear to give rise to more questions than answers regarding the efficacy of school-based optimism interventions and highlight current evidence that without ongoing coaching for teachers, school-led interventions may not be effective (Roberts et al., 2018). This suggests a family-led approach to increasing optimism in autistic children may be more advantageous.

In this section, positive emotions and Broaden and Build theory (Fredrickson, 2003) have been discussed and have highlighted that encouraging positive emotions to be experienced by autistic children may be beneficial to their well-being. Positive emotions are considered buffers against negative emotions and, as seen in Adapted Phenotype Theory, it is proposed that autistic individuals have an enhanced HPA axis, and therefore, may experience more negative emotions. Work regarding understanding their own emotions and generating more positive emotions is likely to be beneficial. Also highlighted is the potential that goal setting (Masten & Barnes, 2018), a strengths-based approach, developing optimism and purpose, may help to develop greater resilience. These are likely to be important components of an intervention for autistic children. The second component of P.E.R.M.A. theory is engagement and this is discussed in the following section.

Engagement

Csikszentmihalyi (2002), suggests that people need to experience 'flow' or 'engagement' as one means to achieve happiness. Being absorbed in an activity that challenges us, is when the rest of the world seems to 'disappear' due to the concentration we draw upon. In this state of absorbtion you lose track of time, and experience 'flow'. Flow theory suggests that to enter into a flow, a person will need challenges or opportunities that stretch themselves beyond their existing skills, alongside clear goals that give immediate feedback (Nakamura & Csikszentmihalyi, 2009). It is said that only when the perceived skills and challenges are just above the person's normal levels is flow experienced; below the perceived level may lead to apathy or boredom (Nakamura, & Csikszentmihalyi, 2009). During a flow experience, the following will characterise the state:

- Concentration on the present.
- Action and awareness merge into one.
- Reflective self-consciousness is lost.
- A sense of control of actions or reactions.
- Time seems to pass quickly.
- The activity is intrinsically motivated and rewarded.

In their discussion regarding the use of interventions to enhance flow, they argue that if practitioners used the principles of flow and focused on the strengths and interests of their clients, individuals would benefit from increased confidence and growth. As Chapter Four highlighted, autistic people often have strong interests through which they can fully immerse themselves (Mottron et al., 2009). This attribute may be advantageous to autistic children's well-being. A programme for parents of autistic children could highlight the value of this innate attribute and encourage parents to foster the interests their children have.

Relationships

Relationships may create and enhance experiences that contribute to well-being, such as meaning and laughter and through this provide meaning and purpose. Supportive relations with others may help us through the downside of life. Taking it upon yourself to do things for others, for example, being kind, can enhance well-being (Seligman, 2018).

Considering possible practical applications of this principle, it has been proposed that cooking may be a useful activity to apply the P.E.R.M.A. framework (Farmer & Cotter, 2021). Cooking and sharing a family meal is said to provide an opportunity for parents to model healthy eating and positive communication about food. It is suggested that food provides opportunities to foster relationships with others by discussing meal planning and preferences, teaching others how to cook, enjoying meals together and sharing cultural transitions (Farmer & Cotter, 2021).

To foster positive relationships in the workplace the following techniques have been offered:

- Have meaningful and mindful conversations.
- Use active listening during conversations.
- Practice kindness and generosity.
- Utilise active constructive responding.
- Show gratitude.
- Be authentic.
- Be friendly and supportive of others.
- Share and celebrate other's victories.
- Build a network of expertise and personal development.
- Identify and contract a mentor.

  (Van Zyl & Stander, 2019, p.9)

It appears that there is an opportunity to foster positive relationships in a variety of ways from shared activities such as cooking to practising kindness and generosity and these could potentially be built into a component of a programme.

Meaning

There have been various models and theories of what meaning in life is (Steger, 2012). One explanation is that meaning is having a purpose and striving to achieve goals (Reker, Peacock, & Wong, 1987). An alternative is that lives are meaningful when the individual understands their life as mattering in a larger sense, having a purpose or going beyond the experienced chaos to make sense (King, Hicks, Krull, & Del Gaiso, 2006). Steger (2012) suggests that meaning is multidimensional, with the first dimension being comprehension, and the second purpose. Comprehension is said to be the ability to make sense of and understand your own life, both internal and external worlds and how you fit and operate in those worlds. These interconnected representations create a meaningful framework for life (Steger, 2012). The purpose is said to arise from long-term life aspirations and motivation to undertake activities relevant to those aspirations. It has been noted (Steger, 2012) that there are tenets of meaning that have consensus across perspectives concerning life stressors:

- Individuals have orienting systems (global meaning) that give motivation and cognitive frameworks to interpret experiences.
- Situations that may challenge or stress an individual's global meaning lead to an appraisal of the situation and meaning being made about the situation.
- The degree to which the appraised meaning is discrepant with their global meaning influences the extent of distress experienced.
- This subsequent distress instigates a meaning-making process.
- Meaning-making are attempts to decrease the discrepancy between appraised and global meaning, make the world meaningful again and their life worthwhile.
- There is an improved adjustment to the stress even if the process is successful.

To illustrate how meaning might apply to families with an autistic child, it is pertinent to explore the meaning for parents whose children live with differences.

The perceptions and experiences of parents whose children were disabled, had life-limiting / life-threatening illnesses or were dependent on technology, were explored in a qualitative study (Whiting, 2012). The researchers aimed to gain insight into the themes of impact, need for help and support and meaning / sense-making the parents had. Parental meaning / sense-making was found to be multifaceted and influenced by various factors. Under the sense-making theme, two categories were identified with multiple sub-categories, most of which were shared across groups. This highlighted that parental meaning-making

shares common features that should be understood when embarking on the development of a parent intervention. The shared meanings across groups were Meaning / Sense-making, Impact, Help and Support and Battleground.

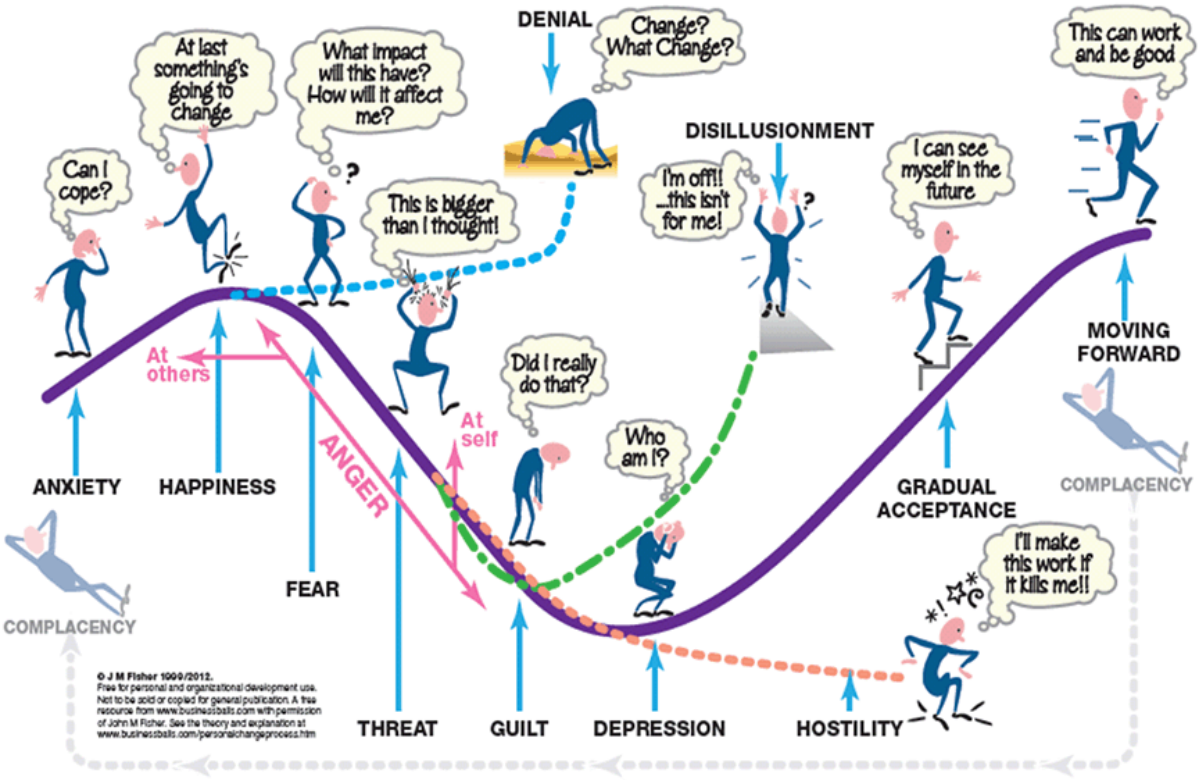
The ‘battleground’ theme had categories of professional mistrust, labelling / meeting criteria and delays in the provision of services or equipment. This is deemed the most important in the context of parental meaning / sense-making and parental perception of their relationships with professionals (Whiting, 2012). Interestingly, one-third of parents in the first set of interviews expressed the battleground theme. In the second interview, when parents were presented with the mind map of themes under the battleground, there was significant recognition by participants of the battleground theme (Whiting, 2012).

A study that was concerned with parents' early stages of *‘coming to understand the child has autism’* (Gentles, Nicholas, Jack, McKibbon, & Szatmari, 2020, p. 478) provides accounts of their psychological experiences before their children were diagnosed. Four meaning-making processes were identified, and these were: defining concerns; informing the self; adapting emotionally and seeing what is involved. An important finding was that some parents experience a period of denial, where there is avoidance of accepting and acting on the possibility of autism and a process of grieving. The grief was said to delay their emotional adaptation, which is specifically stated as *‘releasing culturally based hopes and expectations’* (Gentles et al., 2020, p. 480), though not universal experiences. The authors suggest that interventions need to separately address denial and grief as they are separate sources of delay in engaging in care.

These findings highlight the importance of supporting parents to create meaning around their circumstances and positive perceptions of the family's professional support, as well as supporting parents through the process. I would add a cautionary note that care should be taken using descriptive terms such as ‘grief’ in an intervention. Grief refers to the emotions experienced by a loss and there has not been a loss or bereavement when a child is identified as autistic per se, although there may have been a loss of an anticipated typically developing child. The emotional journey reported by Gentles et al. (2020) may be more helpfully termed as a process of change. Fisher (2012) offers insight into personal change, with stages identified during the transition. Like grief, the stages are anxiety, happiness, fear, threat, guilt, depression, gradual acceptance and finally, moving forward. Other possible stages can be disillusionment, hostility and denial. Fisher also identifies that the transition of change may also bring anger in the early stages and a possible period of complacency in the initial and later stages before moving forward. The stages are visually represented in the diagram of the Process of Transition (Fisher, 2012) (figure +) which may be a useful tool to

use with parents when exploring the emotional journey in an intervention and aid meaning/sense-making.

Figure 12. The Process of Transition (Fisher, 2012)



Regarding supporting and developing meaning for autistic children, a parent programme might encourage parents to consider how their child's interests could bring meaning to them. For example, a child who is interested in natural history could join a conservation group to potentially create greater meaning, purpose, and engagement and potentially build relationships and accomplishments.

This section has explored the concept of meaning and some insights that have been gained from studies with parents into their meaning-making when they have a disabled or autistic child (E.g. Whiting, 2012; Gentels et al., 2020).

Accomplishment

Accomplishment is the pursuit of mastery, competence, achievements, and success for its own sake. This may be achieved through activities such as hobbies, sports or work. As discussed earlier, autistic individuals can form deep interests, and these can again be used to create accomplishment through engagement in these interests.

Seligman's PERMA theory (2018) provides a useful framework with which to guide parents in an intervention. Parents could consider how they may build on each component for themselves and their children. Autistic children's interests offer valuable opportunities to

readily build P.E.R.M.A. into their lives through the components of engagement, meaning and accomplishment.

P.E.R.M.A. Based Interventions

As previously discussed, P.E.R.M.A. may provide a framework in which to assess children's needs and help inform parents on elements of their child's life that may need enhancement. This section reviews findings from studies that have used P.E.R.M.A. as a framework.

To support the involvement of stakeholders in the autism research process, a committee of autistic researchers, the Autistic Researcher Review Board (ARRB) has been set up in the UK to sit within the Autism Intervention Research Network on Physical Health (AIR-P) (Brown et al., 2022). The aim is to ensure that a wide range of diverse perspectives of autistic individuals are considered during the research conceptualisation, process and communication of findings. The aim is also to ensure that research undertaken by AIR-P makes a positive contribution to the well-being of autistic people. To achieve this, they have decided to operationalise well-being within the P.E.R.M.A. framework. Therefore, it is important to consider P.E.R.M.A. interventions that may be included as a choice to promote change.

A recent study aimed to examine the well-being of autistic adults using the P.E.R.M.A. framework in a bid to move beyond deficit-driven research (Grosvenor, Errichetti, Holingue, Beasley, & Kalb, 2023). The P.E.R.M.A. Profiler (Kern & Butler, 2016), a 23-item questionnaire of the five components of P.E.R.M.A. was completed by 517 autistic adults ages 18 years – 84 years. The average overall well-being score was 5.4 out of 10, compared to 7.0 in non-autistic adults in a previous unrelated study. The researchers concluded that the measure needs to be adapted with the co-creation of autistic adults to fully inform the adaptations (Grosvenor et al., 2023).

A single case study has been reported in which P.E.R.M.A. (Seligman, 2011) was used as a framework by multidisciplinary professionals to assess the barriers to learning and development and formulate education plans for a thirteen-year-old autistic male in a specialist educational setting (Roncaglia, 2018). The framework was as follows:

1. *Positive Emotions; how does the individual experience the educational and learning environment daily?*
2. *Engagement; what is the level and quality of engagement past and present?*

3. *Relationships; what is the individual experience of professional/staff members supporting the child?*
4. *Meaning; are the activities pleasurable, and meaningful to the individual or are these set with boundaries of a prescribed curriculum?*
5. *Achievement / Accomplishments; what opportunities has the child been offered to celebrate his achievement, however small, daily? Are these rare opportunities?*

(Roncaglia, 2018, p. 226).

Assessment of strengths and interests was taken to enable the child to engage, and a profile of needs was developed using historical information observations of behaviour and interviews with key adults. The framework enabled the professionals to have a shared understanding through a positive lens, rather than a deficit approach to understanding and supporting the child. The child reportedly progressed in confidence, ability to make choices, attitude to learning, relationships and social skills. The application of this framework enabled the child to progress academically and attend community activities (Roncaglia, 2018). This study highlights the potential of using PERMA as a framework for identifying which elements of a child's life may be enhanced.

Another study, 'Flourish', an intergenerational programme for children and elderly people, uses P.E.R.M.A. as a framework (Gray, Beamish, & Morey, 2020). The programme sought to enhance pupil well-being through participation in bi-weekly activities with elderly care home residents. The activities aimed to encourage intergenerational interactions, build relationships, and evoke positive emotions. Examples of activities are singing, dancing, crafts and reading. Students' accomplishments significantly increased through participation, and an upward trend was found in all P.E.R.M.A. elements.

These studies highlight that using P.E.R.M.A. (Seligman, 2011) in an intervention for children may be beneficial enabling parents to use it to support their children. The following section considers the same for resilience.

Resilience

In this section, the concept of resilience will be explored, and pertinent studies focused on developing children's resilience will be reviewed. There is a large body of literature that is concerned with resilience, with an evolving understanding of the complex interplay of factors that may lead to thriving after adversity.

Resilience Definitions and Factors Influencing Health and Development

Resilience Interventions for Children

Resilience has been defined as responding to adversity or trauma with relatively positive adaption (Luthar & Lyman, 2014). Resilience is a construct combining the dimensions of adversity and positive adaptation (Luthar & Lyman, 2014). From a developmental psychopathology research perspective, adversities are defined by probabilities; a high-risk condition gives a high probability of maladjustment. Luthar and Lyman (2014) give examples of community violence or maternal depression as high-risk factors, and children who experience these show greater maladjustment than children who do not. For non-autistic children experiencing multiple risk factors, such as maternal depression, parents having a low income and low educational attainment, child outcomes are worse than those children who experience a single risk factor (Luthar & Lyman, 2014).

There are studies on developing resilience in children, however, several of the examples are in response to war or disaster. There are fewer evaluated interventions for resilience in younger children. The interventions included in this section were chosen because they focused on younger children (Shoshani & Stone, 2017) and children who are experiencing trauma or ongoing stress, which is relevant to autistic children (Allen et al., 2016).

In the first study, twelve classrooms of children aged between 3-6.5 years were assigned to a control condition and an intervention condition (Shoshani & Slone, 2017). The Maytiv[19] preschool program focuses on four elements of the P.E.R.M.A. model (Seligman, 2011) and related activities for enhancing positive emotions, engagement, relationships and achievement, each with a corresponding module of topics and activities. The programme was not specifically aimed at enhancing resilience, but rather at three areas of functioning: subjective well-being, mental health and pre-school functioning. The modules and focus of activities were:

- Positive Emotions, focusing on emotional management, expression and gratitude.
- Engagement, focusing on character strengths and love of learning.
- Achievement, focusing on persistence and focusing.
- Positive Relationships, focusing on empathy and positive relationships.

[19] Maytiv is a pre-school programme that was developed in Israel for use with younger children, the researchers use ‘pre-school’ to define the age range for the intervention of 3-6.5 years, however, in the UK, children aged 4-6.5 years old would be considered Primary School age.

Teachers were trained in the programme through 34 hours of workshops and facilitated the modules with their classes. Each module provided twenty activities that were facilitated daily for a month. The control group continued with the usual curriculum. Children's positive emotions, empathy and life satisfaction significantly increased in the intervention group and these were not increased in the controls. Negative emotions were unchanged in both parent and child reports (Shoshani & Slone, 2017).

The resilience and coping intervention (R.C.I.) is a group intervention for children and adolescents who have experienced a traumatic event or are experiencing ongoing stress (Allen et al., 2016). The intervention aims to support the identification of thoughts, feelings and coping strategies related to issues (psychological, behavioural or interpersonal) arising from an event or stress. The aim is for the participants to share their experiences, and understand that others have similar thoughts, feelings and coping strategies while processing them and developing new strategies and problem-solving abilities (Allen et al., 2016). The steps undertaken in sessions are:

- Identify a shared problem, either by the facilitator before the session, or group within the session.
- What has or is happening?
- What has changed as a result?
- Exploration of thoughts and feelings related to the problem.
- Identify new problems that are occurring.
- Generate ideas for change.
- Consider the consequences of the change.
- Develop individual and group action plans.

A randomised controlled study evaluated the R.C.I. with University students aged between 18-23 years. Three, weekly sessions were provided to the intervention group of 58 participants, and no intervention for the 61 control group participants (Houston et al., 2016). In the intervention group resilience and hope significantly increased, while stress and depression significantly decreased, and these effects were not found in the control group. There were no significant effects on anxiety or coping for the intervention group (Houston et al., 2016).

Another successful study evaluated the Resilience and Coping Intervention (R.C.I). with children and adolescents from at-risk neighbourhoods (Allen et al., 2016). In this study, 74 participants were aged 5-19 years and separated into age-related groups. Each group received five sessions over two months. The aim is to help children identify their thoughts

and the analysis of the questions related to positive and negative feelings about their participation in the R.C.I. The findings found that there were few negative feelings and children learnt a lot about their feelings and those of others and coping strategies (Allen et al., 2016). Parents reported that children could express their feelings and were getting into less trouble at school. While mean scores for coping increased, these were not significant. There was a statistically significant improvement between the pre and post-intervention scores for the Child Strengths and Difficulties (C.S.D.Q.) Questionnaire and Hope questionnaire. Interestingly, the parent-reported C.S.D.Q. cores were statistically significant for children, but not adolescents.

These studies highlight that there is potential to develop an intervention to support the development of autistic children's resilience. Potentially, this could involve identifying their thoughts and feelings around their experiences, reframing them into more optimistic explanations and building goal -etting into life alongside a strengths-based approach to development. This type of intervention could be taught to parents and may be a highly flexible approach to supporting the well-being of autistic children that parents could adopt. The following section considers more generalised Positive Psychology Interventions (PPI.s).

Positive Psychology Parenting Interventions

Positive psychology parenting research is reported to be in the early stages (Kyriazos & Stalikas, 2018). It has been suggested that the gap may be due to the positive parenting movement that has mainly focused on the 'Triple P' Positive parenting programme, used mainly for populations that need more support than usual (Kyriazos & Stalikas, 2018). Triple P focuses on firm and caring parenting. In contrast, positive psychology parenting is said to be focused on building and broadening positive emotions. A conceptual framework has been proposed: parenting focused on skills, abilities, talents and values before six years of age, that moves to develop and use signature strengths from 6 years of age, with a purpose of well-being and flourishing (Kyriazos & Stalikas, 2018). The following section considers interventions that have been developed for

Strengths-Based Interventions

Strength-based interventions are said to be intentional activities that foster positive feelings, positive cognition or positive behaviour along with the development of specific strengths, (Gander, Proyer, Ruch, & Wyss, 2012). Strengths-based interventions have been replicated to find their effectiveness on well-being and depression (Gander et al., 2012). Nine strengths-based interventions with adults found that eight of the interventions increased happiness and decreased depression in all of the groups. The potential for strengths-based interventions to enhance well-being in autistic children should then be considered.

Flourishing Families (Pentti, Fagerlund, & Nyström, 2019) used an eight-week intervention with parents of non-autistic children. The intervention was strengths-based and focused on engagement, hope, meaning and flow. While they found no significant increase in engagement, meaning or hope, they found that when parents spent time with their children, there was an increase in the flow experiences of the parents (Pentti et al., 2019).

In this context, strengths are described as behaviours and skills that are natural and enjoyable to a person and enable the best performance (Waters & Sun, 2017). Strengths-based parenting, where parents identify their child's strengths and encourage them to use them, has been found to influence teenagers' subjective well-being (Jach, Sun, Loton, Chin, & Waters, 2017). A study of 363 teenagers, found that strength-based parenting and strength use were both significant predictors of subjective well-being beyond the effects of extraversion and neuroticism (Jach et al., 2017). The researchers suggest that parents could help children develop a growth mindset, a belief that an attribute is malleable, alongside the parents to identify their child's strengths. They suggest influencing children's mindsets by using process praise rather than outcome praise, so the child interprets that success comes from the effort that they have put in, rather than the outcome (Jach et al., 2017). A three-week strength-based parenting intervention showed parents how to cultivate their strengths and their children's (Waters & Sun, 2017). Compared to controls, they found increased self-efficacy and positive emotions when parents were thinking about their children, highlighting that strengths-based parenting may improve the well-being of parents as well as children (Waters & Sun, 2017).

It is reported that 30-40% of gifted children may experience emotional, behavioural or social challenges, leading to them not consistently reaching their potential (Armstrong, Desson, St. John, & Watt, 2018). In response to this, the D.R.E.A.M (developing resilience through emotions, attitudes and meaning) gifted edition was developed. The programme is grounded in Rational Emotive Attachment Logotherapy (R.E.A..L). The programme was provided in 10 units, each with a theoretical foundation. The units were:

1. Mental health and gifted literacy.
2. Emotion recognition and social-emotional literacy.
3. Relaxation.
4. More calm-down activities: worry time, imagery, humour.
5. Avoidance and obsessive behaviours.
6. Enjoyable distraction.
7. Meaningful life.
8. The connection between thoughts and feelings.

9. Choosing to think differently.
10. 'Act as if', helpful problem solving and putting it all together.

Perceptions of an experience were presented as 'two sides of the same coin' (Armstrong et al., 2018, p.8), such as challenges also perceived as strengths and transforming difficult experiences or issues into something meaningful. The researchers use the Deep and Wide hypothesis (D.A.W.) (Wong & Worth, 2017). According to the D.A.W. hypothesis, emotional and situational factors may affect giftedness and creativity. “Giftedness” is defined by Wong (2013) in the context on gifted education and highlights its historical defining by Intelligence Quotient (IQ). However, there’s recognition of it not being confined to an educational context but acknowledgement of advancement of their chronological age and/or their outstanding inherent ability in a particular domain (e.g. intellectual, creative, social or physical domain) as outlined by Gagné (2004). Wong (2013, p95) also describes a more nuanced interpretation, a positive psychology one, highlighting that “any definition of giftedness must be related o the child’s peer group, because what defines ‘exceptional’ abilities will depend upon the skills of those against whom one is judged and compared.”

Developing this definition and reflecting on the transformation of “difficult” experiences, these difficulties may become opportunities to 'dig deeper into resources, stretch abilities and endurance, thus, leading to a higher probability of finding a solution and achieving creative personal growth (Wong & Worth, 2017). The D.R.E.A.M gifted edition teaches children to recognise their emotions, social literacy, healthy behaviour and thinking and community engagement (Armstrong et al., 2018). The ten units range in administration time from 5-30 minutes, and each unit includes a song and activity. Music is deemed integral as research shows that listening to music enhances learning, reasoning, critical thinking, and motivation (Armstrong et al., 2018). The analysis found that meaning and mental health significantly increased, and hierarchical regression found that a third of the variability in mental health scores was explained by a change in meaning scores (Armstrong et al., 2018).

This section has considered strength-based interventions that appear to show that these approaches may positively impact children's well-being. There is potential to use a strength-based approach in the proposed programme and this has the scope to bring benefits to both the child and parent.

In this chapter PP. theories and practices that may be beneficial to autistic children have been discussed. The next section discusses what PP. interventions could be adapted to form components in an intervention focused on autistic children and their parents.

Discussion

In this chapter, dominant theories and related interventions from positive psychology have been discussed and have concluded with multi-component positive psychology interventions that focus on children and families. This chapter has highlighted that there has been limited attention to disabled people in both research and practice, with limited insight into autism and positive psychology to date. The following section will briefly outline theories and practices that warrant further consideration for inclusion into the programme.

Theories & Practices to be Considered for Inclusion in the Programme

This chapter has highlighted aspects of positive psychology theory and practice that could be included or embedded in a programme for parents of autistic children. The Spaces of Well-being theory (Atkinson, 2013) aligns with Autistic Development theory, in that both recognise that well-being or affectedness, is not fixed and stable, but instead, context-dependent. It may be pertinent to embed the Spaces of Well-being (Atkinson, 2013) approach into the programme's fabric as a helpful way of framing the possible lived experience of autistic children.

In contrast, the component theories of well-being offer a perspective that appears more stable, and the P.E.R.M.A. model (Seligman, 2011) provides a practical framework to teach parents the components of flourishing. The P.E.R.M.A model was successfully used to develop children's resilience with positive emotions, empathy and life satisfaction significantly increasing in the evaluation group (Shoshani & Slone, 2017). Therefore, using the P.E.R.M.A. model could be helpful for parents and children. A simple visual model could provide parents with the P.E.R.M.A. components to use as an exercise to assess what the child currently has access to in each element. Working on this, parents could develop ideas to build the components that are currently low in opportunity for the child. This may also be a helpful way to display why autistic special interests are positive. Many people still hold the view that special interests are 'obsessions' and are considered problematic. ADT proposes that special interests are positive and provide opportunities for the development of other skills by incorporating them into tasks and activities. Using P.E.R.M.A theory activities with parents may help to reinforce these concepts and show how autistic children have an innate capacity to experience Engagement.

'Broaden and Build' theory would also be a valuable addition to the parent programme. Using 'Broaden and Build' will help to explain to parents the Positive Emotions component of P.E.R.M.A. Whilst 'Broaden and Build' describes the positive impact positive emotions can have on well-being, it also explains the buffering effect positive emotions have on the impact of negative emotions. Emotions such as gratitude have been heavily

researched and interventions have found promising results (Fredrickson, Emmons, & McCullough, 2004). Parents could be encouraged to think of ways to build positive emotions into daily life; potentially enhancing parent's and children's well-being. The programme could explain the theory to parents and offer examples of activities to elicit such emotions, such as gratitude activities. As all families and children are unique, parents could be encouraged to develop their ideas to implement with their families.

As shown in the literature, autistic individuals can tend to get stuck in thoughts (Hare et al., 2014) and this has been linked to anxiety. Activities that will help autistic children decrease rumination and increase optimistic thinking are likely to be a welcome addition to a parent programme. The Resilience and Coping Intervention (Allen et al., 2016), found that children's resilience and hope increased through participation in the programme. The intervention supported children in identifying the problem and what is happening around the problem, generating ideas for making changes to address the problem and making plans and goals to implement the change. This approach may help autistic children move on from rumination (Hare et al., 2014) and approach difficulties from a solution-focused mindset using the A.B.C. model (Seligman, 2007). The ABC model (Seligman, 2007) is potentially an ideal activity for parents to use to support autistic children to move forward from distressing events with a more balanced and optimistic perspective.

To summarise, PP. has much to offer as components of a programme for parents of autistic children. While some could be used as an underlying ethos, such as the Spaces of Well-being (Atkins, 2013), others, such as P.E.R.M.A (Seligman, 2011) could be directly taught to parents to help them understand elements of well-being and drive their attention. There is evidence that the inclusion of PPI.s and PP. theories into an intervention may positively enhance autistic children’s well-being and applying a strengths-based approach may enhance development.

Parents As Intervention Facilitators

It has been suggested that parent training should be included in programmes to enable learning in naturalistic settings, and less structured interventions lead to faster learning. Additionally, they lead children to have higher levels of positive affect and engage in less avoidant and disruptive behaviour, (Grofer Klinger et al., 2013). Reaven, Blakeley-Smith, Leuthe, Moody, & Hepburn, (2012) taught parents how to coach their child in the protocol in their CBT programme 'Face Your Fears'. They found that this helped parents to understand their child's behaviour better and reduce fears. Utilising this type of model, a parenting programme, would have the additional benefits of being highly accessible and cost-effective.

The review of the current literature leads to a compelling case for an intervention to enhance autistic young people and their families' well-being to be led by Positive Psychology. Two studies undertaken by Waters (Waters, 2015) found that authoritative and strength-based parenting contributed to life satisfaction in adolescence. Furthermore, the degree to which parents were aware of their child's strengths was enhanced, as was the degree to which parents encouraged the child to use their strengths (Waters, 2015). These findings suggest that a strength-based parenting programme may enhance the well-being and outcomes of autistic children and their families.

Conclusion

This chapter has considered positive psychology theories and practices that may be included in a parenting programme for parents of autistic children. A strengths-based approach, as advocated for by Masten and Barnes (2018) and Hamley et al. (2018), has the potential to build autistic children's resilience. Historically, most interventions have either attempted to 'normalise' autistic children's behaviour, with some leading to difficulties in later life, such as post-traumatic stress disorder (Kupferstein, 2020), or focus on developing perceived deficits. A strengths-based approach, working with the autistic child's interests and aptitudes is unlikely to cause harm and may provide autistic children with greater opportunities to develop and reach their potential. Positive Psychology Interventions may provide parents with the opportunity to support their children to develop enhanced well-being and resilience, and together with an understanding of autism from ADT, potentially hold greater resources to support autistic children to reach their potential.

The following steps in the programme's development within the thesis are to use the understanding gained from Autistic Development theory, and the findings from this chapter, to develop a programme outline and to seek parents' input into and ideas for further inclusions. The outcomes from the next step, parent focus groups, are reported in the following chapter.

CHAPTER FIVE

SHARING THEIR STORIES:

FOCUS GROUPS WITH PARENTS OF AUTISTIC CHILDREN

Introduction

The previous chapter considered the potential benefit that positive psychology theory and practice may have for autistic children and their families. The proposed research intends to adapt Positive Psychology approaches and embed them into a parenting programme for parents of autistic children. The programme will aim to enhance life outcomes, such as well-being, and decrease stress and anxiety for children and their families. Autism research has attracted criticism for not involving autistic individuals and their families in the research process (Milton, 2014). It has been proposed that interventions must meet autistic children and their families' needs and seek to resolve the current disconnect between research and practice as indicated by Milton et al. (2014, Kourti, 2021) Participatory research methods connect researchers with communities to attain shared goals (Fletcher-Watson et al., 2019). Current topics for participatory research have been identified (Fletcher-Watson et al., 2019). These are:

- Respect – how to respectfully represent lived experience in research.
- Authenticity – how autism communities can shape a research agenda.
- Assumptions – best practice in autistic leadership and community advocacy.
- Infrastructure – how to support and encourage autistic academics and activists.
- Empathy – how to build effective working partnerships.

The James Lind Alliance (“Autism Top 10,” 2016.) has identified the top ten priorities for autism research and these are:

1. Which interventions improve mental health or reduce mental health problems in autistic people? How should mental health interventions be adapted to the needs of autistic people?
2. Which interventions are effective in the development of communication/language skills in autism?
3. What are the most effective ways to support/provide social care for autistic adults?
4. Which interventions reduce anxiety in autistic people?

5. Which environments/supports are most appropriate in terms of achieving the best education/ life/ social skills outcomes in autistic people?
6. How can parents and family members be supported/educated to care for and better understand an autistic relative?
7. How can autism diagnostic criteria be made more relevant for the adult population? And how do we ensure that autistic adults are appropriately diagnosed?
8. How can we encourage employers to apply person-centred interventions and support to help autistic people maximise their potential and performance in the workplace?
9. How can sensory processing in autism be better understood?
10. How should service delivery for autistic people be improved and adapted to meet their needs?

The work pertained to in this thesis aims to meet priorities 1, 2, 4, 5, 6, 9 and 10.

The new framework for developing complex interventions also considers the involvement of diverse stakeholders to be essential (Skivington et al., 2021b). To ensure the autism community was actively involved in planning the proposed intervention, semi-structured focus groups were conducted with parents to gather feedback and foster collaboration. These focus groups took place before the intervention was developed, allowing parental insights and ideas to shape its design.

At the outset, the only predetermined elements of the intervention were the inclusion of Autistic Development Theory and positive psychology exercises. To help parents understand what a positive psychology-based intervention might look like and the types of activities it could involve, they were provided with an overview of the WELLFOCUS program (Riches, Schrank, Rashid, & Slade, 2015).

The WELLFOCUS Positive Psychotherapy (PPT) program is an adaptation of traditional positive psychotherapy tailored specifically for individuals experiencing psychosis. The intervention aims to enhance well-being by supporting strengths and positive experiences. It was developed with the recognition that people with psychosis face unique challenges. An 11-session group programme was developed with each session using exercises that fostered positive emotions with a goal to promote positive emotions, engagement, relationships, meaning and accomplishment. Participants reported increased well-being and positive emotions, suggesting that focusing on strengths and positive experiences can be beneficial for individuals with psychosis. An overview of the intervention was adapted to focus on autism so that parents would find it relevant to their circumstances

and children. The aim of utilising WELLFOCUS was to provide an insight into what an intervention could look like to gather the focus groups suggestions and ideas.

The focus groups provided qualitative insight into parents' experiences to further unpick children's and family needs to further inform the proposed programme. Parents collaborated and gave feedback on the WELLFOCUS outline and shared ideas for inclusion and delivery of an intervention. The parent's focus group discussions were then transcribed and analysed using reflexive thematic analysis.

The planning, orchestration, and analysis of the focus groups were undertaken in systematic stages. This section will describe the design, delivery, and analysis stages.

Primary Research Questions:

Programme Rationale:

As chapters two and four highlighted, research and literature suggest that autistic children's anxiety and mental health problems increase over time, as do their parents. There may also be delays in developing children's functional skills and parents are reported to become 'intrusive' or over-responsive to the child (Drahota et al., 2011). This leads to the postulation that there is a need for a programme to support parents in using positive psychology to increase family well-being and enable their children to reach their potential. What do the focus group parents think about the rationale for the programme?

Programme Outline:

The proposed programme is a set of workshops focusing on managing anxiety and stress developing children's functional skills, and using positive psychology approaches to increase well-being. The primary research questions for this chapter are:

- What do parents think about the proposed programme?
- What factors should be taken into account when developing the programme?

Secondary Research Question:

The programme may be further informed by the lived experience of parents and autistic children. The secondary research question is:

- What insights can parents provide that can enhance our understanding of parental needs and concerns and the needs of their children?

Method

Focus Groups

Focus groups were used as a methodological framework to engage parents of autistic children in the programme's planning stage. Focus groups are advantageous in qualitative methods research as they can uncover the meaning behind facts and produce insight into topics of interest (Grudens-Schuck, Allen, & Larson, 2004). Focus groups are naturalistic, with the fact that participants can say anything that they want. During analysis, the researcher considers the content of the discussion and the emotions, tensions, ironies and contradictions of participants (Grudens-Schuck et al., 2004). Focus groups are semi-structured group interviews, and as such, the social nature shapes the data and leads to the generation of a picture of ‘combined local perspectives’ (Grudens-Schuck et al., 2004 p. 3). It is suggested that a potential decrease in data quality can emerge from a group with highly different characteristics as individuals may self-censor in the group. To mitigate this possibility, multiple sessions should help understand different groups of people's perspectives. The segmented and homogeneous groups help generate good conversations around the topic of interest and enable the researcher to consider group differences (Morgan, 1997). The child's age is likely to lead parents to have different experiences rather than characteristics. therefore, multiple groups were planned with parents of children in three age ranges.

Design

Chapters two and four highlighted that autistic children’s anxieties and difficulties may increase with age (Boulter, Freeston, South, & Rodgers, et al.,2014). Because autistic children’s difficulties may increase with age, it was envisaged that the focus groups were likely to attract the participation of parents whose children represented a wide age range as autism may be identified as early as two years old. To enable all parents to have the opportunity to participate and not become unduly overwhelmed by other families' experiences, participants were separated into groups based on their children's age. Three groups represented the following ages of children and young adults:

- Parents of Primary School-aged children
- Parents of Secondary School-age children
- Parents of young adults aged 18 years to 25 years

Materials

A poster was designed to be a visual representation of the project. The poster identified in steps the following:

- The Need – as identified from a literature review. Anxiety, depression, rumination, parental stress and delays in autistic children's functional skills.
- The Challenges – life-wide approach, experiential learning style, use of coaching and goal setting, creative approaches to accounting for budgetary issues.
- Positive Psychology – an overview of Positive Psychology.
  Our Proposal – adapt positive psychology exercises, consult the community, develop a series of workshops, and pilot and evaluate outcomes.
- Workshop Overview – Strengths identification and development; savouring; good things; strengths; understanding differences; understanding relationships and an overview.

It was thought that a poster would help parents understand the research process and the content we intended to discuss in a visually accessible and meaningful way.

Visual resources provided examples of the strategies that we were proposing to include in the intervention. For example, some visual character strengths pick lists, 'Good Stuff Rubbish Stuff' as a visual tool to help reframe from negative explanatory style and decrease rumination; Family Strengths Tree to acknowledge the different strengths of family members (Appendix B).

Ethical Approval

A detailed description of the research rationale, the research process and the materials intended for use in the focus groups (Appendix E) were submitted to the University's Ethics Panel. The main ethical issue that was foreseen was the distress of participants through either sharing their own experiences or hearing the experiences of others. It was deemed to be of particular concern with the anticipated wide age range of primary school-aged children to young adults. The professional experience of the researcher in facilitating numerous parent groups has found this can be the case and grouping parents into the three age ranges minimises the potential for distress upon hearing the stories of others. Regarding participants becoming distressed sharing their own experiences, it was planned to be flexible and break when and if required to de-escalate the situation. Further to clarification regarding the recruitment of participants, ethical approval was granted for the research.

Recruitment

Recruitment of participants was done by email via third parties and media recruitment.

Email Recruitment

Participant recruitment emails were sent to the following organisations requesting that they forward to parents on their mailing lists:

- 4 local special schools
- A local education authority autism team
- A local autism society
- A local disabled children's charity[20]
- A local parent support group

Media

A local newspaper, The Hinckley Times, produced a one-page article about the research and the focus groups. Subsequently, the local paper and the parent group used social media (Facebook and Twitter) to raise further awareness. A local radio recorded soundbites about the research, planned to be played over a weekend. A local tragedy over the planned weekend occurred, therefore it is assumed that the soundbites were not played.

Participants were contacted via email. Potential participants were thanked for their interest and sent the participant information and consent form to complete and return should they wish to participate. The content of the email follows:

Participant Information Sheet

A participant information sheet (see Appendix C) explained the rationale for the research and seeking parents involvement to share their views on potential future interventions to support well-being among parents of autistic children. The sheet explained that the groups would last approximately ninety minutes and will involve being asked questions and providing feedback on the design. Details of how to join were given along with the date of the focus group.

Participants

- Group 1 – Parents of Primary Aged Children Aged 4 – 11 years.
  Five participants were registered to attend: four attended on the day.

[20] A local charity to support families and children with disabilities.

- Group 2 – Parent of Secondary Aged Children Aged 11 – 18 years.
  Six participants were registered to attend: four attended on the day.
- Group 3 – Parents of Adult Children Aged 18 – 25 years.
  Five participants were registered: four attended on the day.

Procedure

The room had chairs and tables in an oval shape. Two assistants were in place to help with refreshments and general housekeeping.

Upon arrival, introductions were made.

The focus groups were run in two sections; the first was to explain the literature review findings and rationale for the programme, and the second was to provide an overview of the proposed workshops, deliver a script (summary provided within the overview below), and the corresponding poster (see Appendix A-B).

Focus Group Overview

At the beginning of the focus groups a script was used to introduce positive psychology, positive psychology interventions and the rationale for wanting parents to use the interventions at home with their children. The outline of the exercise and workshop was given alongside asking for feedback and ideas. The overview of workshops was intended as a starting point for parents to discuss and generate their ideas. The workshops were based on WELLFOCUS positive psychology intervention (Riches et al., 2015) and adapted to be relevant to autism as set out below:

Parents were encouraged to discuss and input into the rationale, the proposed programme and workshops. The questions asked are listed in Appendix O (and specifically listed on P355 of the Appendix).

The groups were lively, and most participants contributed fully to the discussions. The discussions were recorded for transcription and analysis.

When concluding, the participants were thanked for their contributions and given a verbal and written debrief (see Appendices). Participants were informed that we would keep in touch, and they would have the opportunity to further participate in the research (parenting programme) should they wish to.

Data Analysis

The distinction between "Big Q" and "small q" approaches is key in understanding methodological frameworks and the interpretation of data. This distinction, as discussed by Braun and Clarke (2023), focuses on the underlying research paradigms and the application of qualitative methods. The ‘small q’ approach involves employing qualitative data collection and analysis techniques within a (post)positivist framework. This paradigm often seeks to apply quantitative principles to qualitative data, emphasising objectivity, reliability, and the minimisation of researcher bias. For instance, coding reliability thematic analysis (TA) utilises the ‘small q’ approach by using structured codebooks, multiple independent coders, and measures of intercoder agreement to ensure coding accuracy and consistency. The goal is to produce findings that are as objective and replicable as possible, aligning closely with traditional scientific methods.

On the contrary, the subjective nature of human experience and the co-construction of meaning being created between the participant and researcher is accepted in the Big Q approach. This approach applies qualitative techniques within a non-positivist framework. This perspective views the researcher’s subjectivity as a valuable resource rather than a bias to be controlled. Reflexive thematic analysis, as discussed by Braun and Clarke (2023), harnesses the Big Q approach by highlighting the fluid and organic development of codes and themes, whilst acknowledging the researcher's active role in interpreting data, and understanding knowledge as contextually situated and provisional.

Ensuring alignment between research questions, epistemological stance, and analytical methods within the appropriate qualitative paradigm is essential for enhancing the coherence, transparency, and validity of qualitative research. Braun and Clarke (2023) stress the importance of this alignment to avoid methodological inconsistencies and to promote rigor in qualitative inquiry. In this context, the present study is situated within the Big Q qualitative paradigm, employing reflexive thematic analysis as the chosen analytic method. This approach is underpinned by a constructivist epistemology and values the researcher’s active role in meaning-making. Working independently on the analysis, and drawing upon deep, long-term immersion in the autism community, both as a parent and a practitioner further reinforces the suitability of the Big Q approach over a more procedural, detached small q approach, which tends to treat qualitative methods within a predominantly positivist framework.

Reflexive thematic analysis is a qualitative analysis method that is compatible with constructionist paradigms (Braun & Clarke, 2006) and identifies and analyses themes or patterns within data. A theme is something from the data that is important to the research

question. Thematic analysis requires flexibility and researcher judgment on what constitutes a theme. Reflexive thematic analysis is theoretically flexible (Braun & Clarke, 2006; Braun & Clarke, 2019) and may be approached in different ways:

- *An inductive way – coding and theme development are directed by the content of the data*
- *A deductive way – coding and theme development are directed by existing concepts or ideas*
- *A semantic way – coding and theme development reflect the explicit content of the data*
- *A latent way – coding and theme development report concepts and assumptions underpinning the data*
- *A (critical) realist or essentialist way – focuses on reporting an assumed reality evident in the data*
- *A constructionist way – focuses on looking at how a certain reality is created* by the data

(Braun & Clarke, 2006; 2013)

Reflexive thematic analysis may be inductive or 'bottom-up', or theoretical and 'top-down'. Inductive analysis does not have a pre-set coding frame or analytic preconceptions of the researcher, and is, therefore, data-driven. The research aims to involve parents in the planning stage in creating the programme; therefore, an inductive approach is deemed appropriate in this research project.

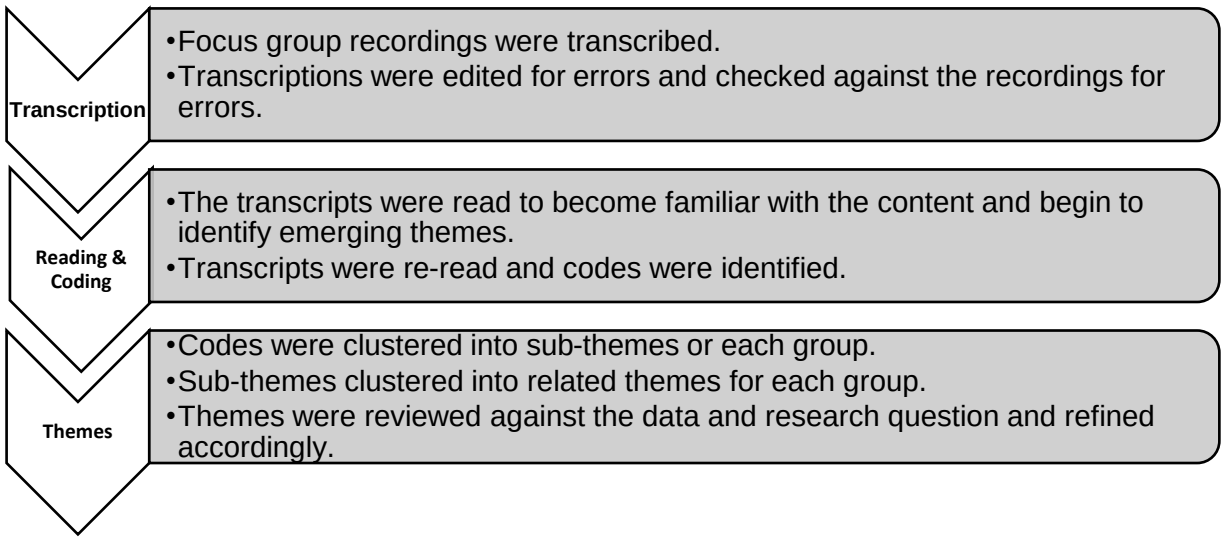
Thematic analysis allows for the development of themes at two distinct levels, semantic and latent (Braun & Clarke, 2006). The semantic level identifies the themes within the data's surface meaning and does not attempt to go beyond. Semantic analysis organises the data to show patterns and interprets the importance of the patterns, meanings, and implications. The latent level enables the researcher to move beyond the descriptive towards identifying the underlying ideologies that may be theorised as forming semantic content. For this research, the analysis's focus is on the semantic level, with some latent analysis.

Table 7. The Phases in the Thematic Analysis Process (Braun & Clarke, n.d, Braun & Clarke, 2006 p.1)

Phase	Process Description
1. Becoming familiar with the data	Transcribe data, reading and re-reading the transcripts
2. Coding	Coding interesting features of the data systematically across the entire data set. Undertaken separately for each focus group
3. Generating Initial Themes	Collating codes into potential themes, gathering all data for each potential theme
4. Theme Review	Check the themes against the codes to ensure that the themes fit the coded data
5. Naming and Defining Themes	Refining themes, the story the themes tell, generating clear definitions that describe them.
6. Producing the Report	Providing extract examples of the themes, relating to the research question and literature

The process undertaken for this analysis was as follows:

Figure 13. Systematic Process of Transcription & Thematic Analysis of Focus Group Data (Braun & Clark, 2021)



Transcription Stage

Each recording was transcribed after listening to familiarise each participant's voice. Each participant was asked to identify themselves with a number provided to them to decrease errors when transcribing. Some words were not intelligible, or more than one participant spoke at the same time, which was reflected in the transcriptions. Noises and other non-verbal body language that could be heard, such as banging fists on the table, were also recorded in the transcriptions.

Reading and Coding

The transcripts were read for initial errors and corrected. The transcripts were then re-read alongside listening to the recordings and checked for errors or omissions. Once the checks were undertaken, the transcripts were re-read to begin to identify codes. Codes are the generation of labels that capture features of the data relevant to the research questions.

The decision to divide participants into three separate groups was informed by prior experience, which has highlighted the differing needs of parents and children across various chronological ages. This approach allows for a more developmentally sensitive understanding of their experiences. Moreover, conducting the analysis separately for each group enables the identification of potentially more nuanced and age-specific themes, offering deeper insight into how developmental stages may shape perspectives and needs.

Further to this it would be helpful to undertake the analysis separately to highlight a possible more nuanced themes for different ages and stages of development.

Generating Themes

The codes were then clustered to generate themes and sub-themes that created broader patterns of potential themes. The potential themes were then checked against the coded data and transcripts to ensure they were representative. During this stage, the potential themes were adapted, re-named or discarded.

The themes were divided into sub-themes and themes, the latter being the overarching context of the story.

It should be noted that the thematic analysis was not a linear process. There were numerous moves backwards and forwards through the stages as I became more engaged in the data and generated labels to capture the meaning, as has been described by Braun and Clarke in their discussions regarding reflexive thematic analysis (Braun & Clarke, 2006; 2019).

Focus Group Analysis and Discussion

Primary Research Questions

This section provides an overview of the themes, sub-themes and codes that emerged about the primary research questions:

Programme Rationale: What are the parent's thoughts regarding the rationale for the programme?

Programme Outline: What do parents think about the proposed programme? What factors should be taken into account when developing the programme?

Category: Feedback for Content and Delivery Overview

The table below provides an overview of the themes, sub-themes and codes that were identified concerning the two primary research questions. The figure shows that all groups responded positively to the proposed programme concept and advocated for a whole-family approach and early intervention. As the figure shows, while three codes are shared between all focus groups, parents from each group made different suggestions for the content, which is likely reflective of their current circumstances and the age of the child. The volume of input from the groups was not equal, which is reflected in the table below. This is discussed later in the section.

Table 8. Category: Feedback for Content & Delivery Overview All Groups

		Group Codes		
Theme	Sub-theme	Primary	Secondary	Young Adult
Feedback for Proposed Programme	Content	Positive response to the programme		
		Guidance for parents		
		Advocacy for parents		
		Need for a positive perception of children		
		Develop strengths		
		Include positive adult stories		
		Co-morbid conditions		
		Bereavement		
			Parental over-involvement	
			Develop strengths	
			Celebrate success	
				Need for goals
				Adaptable for adults
				Manage stress and anxiety
				Break family cycles of stress
				Strategies for parent stress
	Delivery	Accessibility		
		Involve the whole family		

		Group Codes		
Theme	Sub-theme	Primary	Secondary	Young Adult
		Value peer support		
		Experiential learning		
		Early intervention		
		Parent stress may hinder outcomes		
				Early intervention would lead to money-saving long-term
	Additional Resources	Involve schools		
		Involve support workers		
		Online support		
		Online follow-up		
		Online resources		
		Website		
		Online updates		
		Live chat support		
				Use social media

The following will discuss the codes of the theme of proposed programme feedback for each focus group.

Category: Feedback for Content and Delivery Focus Group 1 Parents of Primary School-Aged Children

In this focus group, parents focused on the proposed programme's concept and contents more than the other two groups. This may be because the parents are in a 'need to know' stage which is discussed later in this chapter, and were therefore more heavily invested than the parents of older children in the other groups. The parents were provided with an overview of the rationale of the proposed programme, and one parent stated, in response to how children may have escalating difficulties:

> *"[child] is described perfectly, with his issues…"* (FG1 line 64)

Parents expressed a positive response to the programme's concept (FG1 lines 162, 178, 755, 764, 856) and gave interesting suggestions for the programme and the delivery. Regarding the programme's delivery, parents described a need for a programme that included both parents and the wider family, including siblings and grandparents (FG1 lines 164, 165, 185, 187, 188, 198, 202, 269). Parents described the value of attending with other parents, with a high value placed on peer support (FG1 lines 118, 132, 246, 254, 542, 842), both online and in person.

Parents suggested that it was important to provide a programme as soon as possible after a child is diagnosed with autism (FG1 lines 549, 553, 782), acknowledging that there is a need for timely information, advice, and guidance to help parents understand how to support their child. One stated:

"A really good point is that when you are diagnosed when your child is diagnosed, you feel like you are being diagnosed too. I know I did, 'cos you thought right you have to deal with it now, it's there, it's something that you just have to get on with. There is a bit of bereavement or trauma or concern over what is going to happen in the future, yeah, umm, but I think it's something that you need to be taught about, so it's OK it's there, come on let's learn about it and get on with and that positive message is really important 'cos otherwise you're like I can't do anything you know, I can't help them, I'm not going to try and teach them anything 'cos they can't learn it…" (FG1 Lines 503-509).

One parent suggested that delaying parental access to a programme may lead to some access to the 'dark side' of the internet (FG1 line 782). This statement is interpreted as the potentially unscrupulous websites that offer questionable therapies, and so-called cures that may be potentially dangerous.

Parents thought that people who wanted to participate in the programme would get a lot out of it (FG1 line 764), but parental stress or lack of commitment may hinder outcomes, (FG1 lines 527, 755).

There was a reference to the potential co-morbid conditions that may arise and the need for professionals to both acknowledge these potential difficulties and support children and families with them, (FG1 line 111):

"They kind of label the autism and forget everything else, like there's the label, but they forget all of the co-morbid conditions that can go with them, that also need support as well." (FG1 line 111).

Parents offered suggestions for programme delivery, accessibility questions were raised that were operational in nature, such as times and days of the week, with suggestions of offering a range of choices to parents and childcare provision, (FG1 line 265).

"I think that a great idea, lots of services aimed for children, or you always assume that Mums' gonna go, be on Tuesday morning, ten till eleven; people out there will have jobs, people work, it not, support that's offered is very old fashioned, from the olden days, people work, have jobs, I mean there are things that I could have accessed, but I couldn't, I work, my son's not been able to access, he's at school." (FG1 Line 178).

Parents emphasised the need for online resources to support the implementation of the programme at home, suggestions included a website, live chat for advice, an online forum, follow-up and expansion via email, videos, resources to use and readily accessible information, (FG1 lines 809, 811, 822, 826, 828, 830, 839, 846).

"If you have a website with the exercises on them you could keep practising them. Also, have one of them, you can have or err, what's that thing, maybe live chat? Where you can get online advice straight away exactly when you need it. Maybe have some volunteers [talking over]. Umm yeah, that's a good idea." (FG1 line 809).

Parents expressed the need for an approach that balances supporting the child's difficulties and developing strengths. Parents also wanted 'trusted' information and guidance from professionals. Parents placed a high value on providing insight and examples of autistic adults to decrease the uncertainty about the future, (FG1 line 506).

"…and like there are some really inspirational speakers out there you know with other conditions, co-morbid, I know they cost money, but umm to have them, but just people who are getting on with their lives, who aren't being affected, you know, hugely, who you would walk past in the street and you wouldn't know it about them." (FG1 line 510).

Parents recognised the value that having an autistic adult speak would have on creating a vision of what life may be like:

"I have had parents who are like to see people with autism speak standing up there, talking and seeing how amazing and what they are doing with their lives makes such a change, cos you do have that feeling of what is it going to be like." (FG1 line 476).

Parents placed a higher value on local people than those who are widely known:

"In a professional environment as well cos social media, online groups things come up and someone like Richard Branson or something, I don't know, but this man's a millionaire, and he has autism, blah blah blah, but yeah but it would be nice, you take everything with a pinch of salt that you see online, but to see a workshop and how it was presented to you, you're like goanna go it's going to be a lot better than seeing snippets online." (FG1 line 479).

"Get them from the area, Yeah yeah." (FG1 line 486).

"*This millionaire from god knows where is not going to have the same impact as this guy from Leicestershire or this guy from Warwickshire."* (FG1 line 489).

Parents wanted to see autistic adults living ordinary lives with life being OK and embarking on ordinary activities, such as long-term relationships:

"Just like normal people, you know this guy's grown up he's got children." (FG1 line 495).

"He's got married." (FG1 line 496).

"It doesn't have to be that these guys changed the world, it can be like this guy is grown up and it's ok." (FG1 line 499).

Category: Feedback for Content and Delivery Focus Group 2 – Parents of Secondary School-Aged Children

As previously reported, parents of primary school-aged children offered more feedback and input into the proposed programme than the other two groups. Parents in this group were, again, supportive of the proposed programme and expressed a need for a programme that is positive about their children (FG2 lines 457, 533, 682, 683,) and provided a whole family approach (FG2 lines 787, 790):

"*Yer definitely sounds like something I'm more than willing, I like that it's all based around positivity as well that's... the way they've been going wrong for such a long time.. not just*

with autism either, just with children in general it's all 9-1 ratio, negative to positive." (FG2 line 683).

Parents discussed issues of accessibility, suggesting course presentations during school hours, though highlighting difficulties attending during working hours, and accessibility regarding specific learning difficulties (parent dyslexia) (FG2 lines 498, 792, 794, 796, 801).

Parents talked about the need for course presentation post-diagnosis and suggested that had they had access to the proposed programme their child would not have suffered so much (FG2 lines 232, 235, 845, 847):

"After the diagnosis, I could've come to a course like this straight away, I don't think my son would have suffered as much." (FG2 line 845).

Parents felt that the current practices were 'punishing' to children, lacking acknowledgement of strengths and successes (FG2 lines 233, 279). There was hope that the proposed programme would decrease parental over-involvement (doing too much for their children that decreases functional skill development) and would aid the independence and flourishing of the child:

"*I think because I've had less support I've become very, very overprotective over my son, and both my boys are terrible at saying I'm overprotective, which then means they're not flourishing as well as they should because I'm too scared to let them do things."* (FG2 line 702).

Overall, parents were supportive of a new programme that would support them and were aware of their over-responsivity towards their children.

Category: Feedback for Content and Delivery Focus Group 3 – Parents of Young Adults

Parents responded positively to the proposed programme and saw the benefit of utilising social media to support parents:

"…social media it is parents, families, like Warwickshire voice, speaking through things like that on how to find out. I mean you can get onto a website to find out… and at the end of the day it's gonna be something like that, a parent's forum and it'll be my child's doing this, help and someone will." (FG3 line 545).

There was a suggestion that there should be the inclusion of family members:

"Not just the parents, but if the person has close contact with extended family." (FG3 line 96).

"To include the whole family, so if at some point your parents aren't there and they stopping with extended family." (FG3 line 98).

Timely support to enable the family to implement strategies would lead to less need from professionals and cost savings in the future:

"Also, sorry, if you can catch them at a young enough age, and engage the whole family, so the family has all the strategies or at least a good set of strategies to help develop they're gonna need less input from the powers that be, social services, occupational therapists and stuff. So ultimately you are saving the NHS so much money, because, and they are getting it supplied and you are not getting people telling you, your son, your daughter is useless, this is all they're gonna amount to, we will just treat them. You just sit out there and have a bickie and a cuppa and leave it to us. And end up with a gibbering mess anyway." (FG3 line 232).

Parents shared the difficulties that they faced with Grandparents showing a lack of understanding of autism and the additional stress that this can lead to, hence the need for whole family involvement in a programme:

"My parents, well particularly my Dad couldn't get his head around it, there's nothing wrong with him, because, eye contact. Well, it was the 'elephant in the room', you couldn't discuss it, because it wasn't interesting, because when he (the dad) was a child they were all locked up and put away, never seen." (FG3 line 717).

*"So, you have in the family dynamics, you haven't got total buy-in from the outside family. You get that stress because you can't, you have to tiptoe around the subject. They took him on holiday, my Mum and Dad did, we warned 'em…..but when we came back it was how they'd been brought up, not autism, just how they had been brought up", (*FG3 lines 724).

Parents suggested that a key element should be an emphasis on the management of stress and anxiety:

*"No, I think the emphasis is on the stress and anxiety…I think that's the biggest issue…" (*FG3 line 821).

"But the stress and anxiety, sometimes if they see that, I mean, [child} sometimes gets a kick out of it." (FG3 line 828).

There was recognition of the cycles that can be created between parents and their adult children:

"It is and to try and break that vicious cycle, otherwise all you do is bounce it off each other." (FG3 line 836).

“Round and round it goes.” (FG3 line 838).

“Walking a bit of a tightrope really, you’re gonna fall, but the way you fall will be the difference.” (FG3 line 691).

Parents requested support for developing their coping strategies to decrease child and parent cycles:

“The adult coping strategies, how we cope, ‘cos like you say, the stress and anxiety rubs off on the children onto us, and it’s a vicious circle because it goes back and it’s very hard to break.” (FG3 line 687).

A parent emotionally expressed the impact that simple de-escalation techniques have had on her son’s life after the researcher discussed these techniques as part of the programme:

*“…he was in full meltdown, and it can take hours no, days to bring him out of it, she made him do these simple breathing techniques [clicks fingers], and within ten minutes he was well on his way to recovery! I have never seen anything like it, I sat in the corner of my living room and cried [choked up and started crying] why couldn’t anyone have shown us that? [choked up] years ago, it could have saved him so much heartache and pain, because having these meltdowns must be absolutely soul-destroying for them.” (*FG3 line 469)

During the focus group discussions, parents openly discussed challenges that they and their children have faced with stress and anxiety. The quote above provides insight into the level of distress that young people can face in their daily lives. This young person had experienced events that were reported to last up to days at a time and presumably became life-limiting for both the young person and the family. This example gives insight into the level of distress experienced and the ease with which the young person learned how to de-escalate his emotions and experiences with appropriate techniques and guidance. The mother’s response to the new strategy was questioning and distress, with hindsight, some strategies could have helped her child. The parent questioned why no one made this strategy available to him before, with an underlying perception of being let down. The parent interestingly expanded on her insight and suggested controlling reactions to anxiety and distress may lead to other forms of development:

“Well, that leads to everything else anyway, because once he knows how to control that, then surely it’s going to lead him forward into doing better in other things as well. Because he knows nothing’s the end of the world. If you're not gonna die in ten minutes from something, then it’s not that important, go get through it, come on, let’s get it done.” (FG3 line 480).

This statement from the parent reflects empowerment, of both the young adult and parent, with a shared understanding that they can move forward from events.

Parents responded positively to the proposed programme both as a concept and the proposed content. Parents of young adults discussed the most significant intervention areas for them: strategies to cope with their children's anxieties, distress and stress of the parent.

Secondary Research Question: Needs and Concerns of Parents

The following section of the chapter addresses the secondary research question: What insights can parents provide to enhance our understanding of parental needs and concerns and their children's needs?

In the following sections, the themes that were identified from the focus groups will be discussed. The tables provided for each theme provide an overview of the themes, sub-themes and codes that were identified from each group.

Category: Current and Previous Provision

The figure below provides an overview of the sub-themes and codes related to the theme Current and Previous Provision for each group. In this theme, all groups shared codes of ‘diagnosis’.

Table 9. Category: Current/Previous Provision Overview All Groups

<table>
<tr><td colspan="2"></td><td colspan="3">Group Codes</td></tr>
<tr><td>Category</td><td>Sub-theme</td><td>Primary</td><td>Secondary</td><td>Young Adult</td></tr>
<tr><td rowspan="9">Current Previous Provision</td><td rowspan="9">Diagnosis</td><td colspan="3">Diagnosis</td></tr>
<tr><td colspan="2"></td><td>Importance of early diagnosis</td></tr>
<tr><td colspan="2">Post diagnosis support</td><td rowspan="2"></td></tr>
<tr><td></td><td>Need to push for a diagnosis</td></tr>
<tr><td colspan="2"></td><td>The child’s presentation made diagnosis difficult</td></tr>
<tr><td colspan="2">Medication</td><td rowspan="3"></td></tr>
<tr><td rowspan="2"></td><td>Co-morbid diagnosis</td></tr>
<tr><td>Polypharmacy</td></tr>
</table>

		Group Codes		
Category	Sub-theme	Primary	Secondary	Young Adult
	Support & Interventions			Lack of early intervention
				Good Support
			Seeking support	
			Need to push for support	
		Lack of support		
			Inappropriate support	
			Strategies/support not working	
			The child not meeting the criteria for support	
			Child refuses support	
				Inappropriate transition (child to adult services)
				Parents left without support
		Postcode lottery		Postcode lottery
		Family Support Needed		
			Negative focus	
			Lack of balance between strengths and weaknesses	
		Accessibility issues (times)		
				Systematic failure

		Group Codes		
Category	Sub-theme	Primary	Secondary	Young Adult
		The dark side of the internet (questionable therapies)		
	Professionals	Need training		Need training
		Competence questioned		Competence questioned
		Negativity		
		Lack of understanding of sensory needs		
				Limiting beliefs
			Need to listen to parents	

Category: Current/Previous Provision Focus Group 1: Parents of Primary School-Aged Children

Parents discussed the diagnostic process, with some finding this easy, and others feeling that professionals involved with the family had missed signs or had experienced delays. This led to some parents fearing that other families were slipping through the net, and delays may have affected children's development, (FG1 lines 106, 136, 148, 149, 152, 155, 156, 233). Parents valued the diagnosis suggesting that it leads to answers and support, (FG1 lines 244).

A reported lack of post-diagnostic support for some parents was not shared by others, indicating that there may be a 'post-code lottery' for post-diagnostic support, (FG1 lines 90, 93, 94, 96, 98, 104, 106). While there were differences in the provision, some parents alluded to the financial considerations of the provision being offered locally [EarlyBird][21] the viability of running parent courses with low numbers and how this leads to uncertainty as to whether the courses will proceed (FG1 lines 204, 207, 209). Parents advised that in their

[21] EarlyBird is an early intervention parenting programme from the National Autistic Society that Local Authorities deliver at a local level

previous experience, some parents had requested courses from local support networks and did not attend when they were provided, (2 FG1 lines 13, 215):

*"Only three parents on the course but usually can't run below 5, had the numbers to umm start it, but umm only 3 of us turned up on the first week. Umm, they had to decide whether or not to continue to run it, so two ladies were running it, so was it worth their wages to like run the course. Luckily, they did decide to keep running it." (*FG1 line 207).

Category: Current/Previous Provision Focus Group 2: Parents of Secondary School-Aged Children

The discussion under this theme was broad, and parents highlighted challenges that they had faced, from a late diagnosis due to a perceived delay of professionals picking up signs (FG2 line 263), to parents needing to push for their child's needs to be met (FG2 line 300). Parents desired support and strategies to help their child and reported that there was a lack of help. Parents reported a lack of parent groups to help with strategies to support their children with challenges they faced, but had found that parent groups were used to offload by other parents and were therefore deemed unhelpful (FG2 lines 336, 364, 365, 370, 371, 376).

While a 'social and emotional group' was made available for one child (FG2 line 381), the parent explained that the strategies could not be implemented at home:

"umm wasn't really taught anything about it, all he done was talk, he come home with a load of paperwork and stuff and he couldn't explain any of it to me, couldn't tell me what it was he was supposed to be doing with it, so it's just dumped in a cupboard now." (FG2 line 383).

Another parent's experience of such a group involved last-minute changes and poor communication - there was a change from the planned parents and children's groups running concurrently for six weeks to a 2-week group for children only:

"Son's put down for this course, and we were told its six weeks, parents go to this course at the same time, and its and when we actually got to going, and we went for the first one, and they told us its two weeks now and its child only" (FG2 line 386).

A further complication is added by the child's response to support and refusal to engage:

"*My son won't go to anything, even if we're offered things he won't go."* (FG2 line 391).

"*It took us eight CAMHS meetings to actually get him to come to there, to come into the house, he stayed in the car for three meetings, in the car park."* (FG2 line 453).

The deficit-led approach of CAMHS was of concern to parents as there was a perception of parents not being able to balance the child's strengths and weaknesses in discussion with professionals, and this further impacted the child:

"I think it's very difficult when you go to your CAMHS support because you have to sit there and tell them all the things that are going wrong, in front of your child, and I don't agree with that, because he comes out of that feeling crap. Because if I go in there saying oh yer, we done this and we done this and we done this positive stuff they'll be like, so where's your issue? I have to go in there and say well it's this, this and this. And my son comes out there and he's like, oohh." (FG2 line 439).

To decrease further negative impact on the child, parents developed strategies to engage with professionals while protecting their children from further perceived harm:

"I've written it down before now, I've written it and given it to them." (FG2 line 444)

"Yesterday I opted not to take [child], deliberately, because they don't need to talk to [child], because whatever they say [makes a noise], it's me they need to talk to, and it's me they need to help not him." (FG2 line 446)

The quote above is indicative that parents are aware that they play a crucial role in supporting their children. The quotes above appear to indicate that the system that they are currently in, is not wholly meeting the needs of the children or the parents, and parents appear to be developing strategies to help them navigate through this with more success.

The parents explained that no help was available until the child received a diagnosis. One parent reported no acknowledgement of sensory challenges until a Doctor acknowledged them in his report (FG2 line 178). Therefore, support and intervention were medically led in this case.

Parents were clear about the lack of support and guidance that they experienced post-diagnosis and the need to push to receive support from various teams:

"Support? You get given a diagnosis and that's it, you know?" (FG 2 line 190).

And:

"But no support to do anything with it, apart from medication, which is horrid." (FG2 line 192).

"There's nowhere to go after you've had 'em I had to kick and scream to get 'em to CAMHS for autism outreach to get involved, you, you get a diagnosis and that's [bangs table] that's it! [bangs table].

nobody tells you where to go, what to do! You don't know anything about autism." (FG2 line 810).

"*I was actually told on the course, the parent course I went on that wasn't particularly good, and obviously, all the parents were downloading as I said and the guy that ran it that I seen at CAMHS he said, that basically we had to accept that that is how it is. You. Are. On. Your. Own. Which I found useful, because you can take it a bit personally, like why is nobody helping me? So at least I knew then that this is how it is for everybody, so I could accept it and get on with it then."* (FG2 line 814).

It appears from parents' comments that support and guidance do not automatically lead to a diagnosis of autism (FG2 lines 822, 825, 826). Access to support is based on parental demand and other factors such as co-morbid diagnoses, highlighting a reactive approach to supporting children and families, rather than a proactive, preventative approach. Parents reported that children were receiving multiple co-morbid diagnoses to explain their child's behaviour or presentation:

"My son has about nine different diagnoses." (FG2 line 165).

"Autism, OCD, depression, anxiety, [inaudible] flight disorder, sensory processing disorder, quite a few." (FG2 line 167).

As well as children being diagnosed with multiple conditions to explain their presentation, some children were also prescribed multiple medications, (FG2 lines 192, 193, 195, 198, 202, 203):

"Errr, is on al[inaudible] for his ADHD, on 200mg of Cetirizine[?] was on Clonidine but his just reduced that for a new medication which is just bin legalised istrivin[?] think it is. And err, what else is there, oh he's on Circadian and melatonin to help him sleep as well," (FG2 line 198).

"We're on Occlitene[?] to 200mg and melatonin, which doesn't bother me." (FG2 line 206).

While, as the above quote shows that some parents are not concerned about the medication their child is being prescribed, another parent expressed:

"But, you know if it helps him cope with the world then I'll give it to him, but it's not right, there should be other ways." (FG2 line 195).

Additionally, the same parent stated:

“He’s on 200mg, which is the highest dose even an adult could take, but it helps with his depression, his anxiety his OCD. If I could do something with the core, the autism, then I wonder if that would hopefully, disappear.” (FG2 line 203).

While this parent accepts that the medication helps her child cope, she questions the ethics of medicating the child and expresses a desire to help him other than prescribing medication.

Parents have highlighted a lack of post-diagnosis support to help them understand autism and support their children appropriately. The barriers and challenges experienced included attempting to access support, related to referral, children being exposed to negative focus, lack of child engagement, diagnosis of co-morbid conditions and polypharmacy. The parents' experience was that provision was offered when children and families faced significant difficulties, highlighting a reactive rather than a proactive approach to support and guidance.

Category: Current/Previous Provision Focus Group 3: Parents of Young Adults

Most discussions within this area were related to historical issues that families and children had faced from early childhood to young adult life. Concerning seeking a diagnosis, parents discussed the misunderstanding that professionals have with eye contact, one stated:

“We took [child] at 18 months because we knew there was something wrong, but where we were at whiz, the woman, the paediatrician said he’s not got autism, cos his got eye contact, and that was it, she wrote him off.” (FG3 line 194)

Parents discussed the additional challenges that they faced as a family because of delayed diagnosis and how they hope that interventions such as the proposed programme would lead to enhanced outcomes:

“And it gotta be better for the parents and the babies if they can diagnose them earlier, and not them have like I had, thirteen years of learnt behaviour to then manage what you’ve got... and we’re then unpicking, thirteen years of”

“Damaged goods.”

*“Yeah, because they missed out that he was autistic and so he just developed all these ways of avoiding doing stuff and now trying to get him to do stuff is quite challenging.” (*FG3 lines 183)

Parents felt that early intervention that involved the whole family would not only support the child’s development but would be cost-saving to various departments in the long run:

“Also, sorry, if you can catch them at a young enough age and engage the whole family, so the family has all the strategies or at least a good set of strategies to help develop their gonna need less input from the powers that be, social services, occupational therapists and stuff. So ultimately you are saving the NHS so much money,” (FG3 line 232).

Parents were aware of the lack of resources for autism and the impact that this has.

“I think the other thing is... unfortunately I think a lot of it is down to funding, and that is, America may have the funding but this country, I don’t think it’s one of their priorities. Unfortunately, and funding is always fundamental to anything. More funding, more research, more people can get diagnosed. Cut back on funding, like with everything else and people will go undiscovered and wonder when they leave school with no good grades... what happened then? And it’s too late” (FG3 line 211).

Parents had lost support due to funding cuts, but how it was handled led to a breakdown of trust with the social care team and left the family with a sense of unfairness and apparent disrespect for professionals:

“He was meant to have ‘respite’, two nights three days in the week then a weekend the following month. Then we were told the service’s cut, everybody’s cut it then we had this briefing, we found out that only four or five families lost this, they lied... and I called him out on it, not a fight but I called him out and I just kept going on and on and we got a private consultation and he couldn’t answer why we lost our respite when other families got it, and we were like so where’s our respite? Our break?” (FG3 line 267).

“Exactly, the prime example was the head of, I think he’s left now, the head of Warwickshire, what was his name? That knob? [laugh] oh sorry,” (FG3 line 260).

Parents were reflective of Social Workers'' caseloads, and despite reporting that their social worker was good (FG3 line 254), this led to the parents dealing with situations alone, (FG3 line 255).

Parents also spoke of professionals' perceived attitude to their child or family and suggested limiting beliefs about the child or young person's potential. Misconceptions were reported, some of which led to the child being singled out by other children:

“I was walking down one night with [child], and this little boy was walking behind us with his mum, and I heard the little boy say. Oh, that’s [child], his brain don’t work. And the mother said how do you know that? And he said because our teacher told us.” (FG3 line 504).

Other experiences led parents to hold their own limiting beliefs about their child and what the future would be like:

“The social worker person we had turned around and said to us, our son is so broken he will never mend.” (FG3 lines 253).

“It happens in all the families because that’s what you’re told you have to do, to be like, they have this label, you have to protect them, they’re fragile, they’re anything but fragile! Not bloody fragile to be fair.” (FG3 line 418).

“Quoting a social worker, “It’s not possible for them to lie.” (FG3 line 424).

“You’re told he’s got autism, so you start treating him different, and then they come down and they make it worse.” (FG3 line 403).

Parents felt that the focus of support and intervention they received was unbalanced and did not acknowledge the child’s strengths or achievements:

“But I think it’s gotta come down from the ground up because it’s all wrong. They just want to look at all the bad things, and they don’t want to acknowledge any of the good things. Never once, through any of the interventions that [child]’s had since he has been diagnosed, no one has ever said, well done. They’ve said, well you can’t do this because, and you’re gonna have to do this.” (FG3 line 783).

As well as interventions being perceived by parents as being unbalanced, some led to increased difficulty as they failed to account for the young person’s differences:

[Discussing Cognitive Behavioural Therapy] *[example of what a therapist said] ‘So what you got to do is when something comes up, and you’re not quite sure, you just got to think about it a different way.’*

“He’s already thought of it a different way! Why you’re saying it and some of the biggest meltdowns we had was when someone said that’s what they did. That’s what the occupational therapist did.” (FG3 line 791).

Further examples of misdirected support were from a provider for the Department of Work and Pensions. The Support Worker failed to deliver the promises made to the young person and produced an inaccurate CV for him. After five months, they told him he was not a suitable candidate and due to conflicts of interventions with another support programme, made him choose whether to carry on with the scheme:

“We’ve just been through with [child] a centre and he got put through a scheme to enable disabled people to get into work... we had an initial meeting with his.. support worker as such and she guaranteed that within four or five weeks they would find some sort of voluntary placement for him. The course only lasts for six months four and a half, five months in, they

signed him off. Because they said they don't think he's a suitable candidate and [pauses to take a deep breath] and that other interventions he is having interfere with these people. So, they signed him off. They actually gave him the choice, said do you, want to continue on with the scheme, or continue on with your other intervention? [child] made the choice to continue on with, carry on with the other intervention, so that's where we are. But during this, she produced a CV that was an absolute pack of lies, that she was expecting [child] to present for job applications and stuff." (FG3 line 311).

Describing the inaccuracies and misleading CV that was produced by the Support Worker, the parent stated:

"It was riddled with spelling mistakes, and it was just like someone had given you drop-down boxes, of specific questions where you can tick specific answers, a b or c, he's a team player, no actually he's not a team player... he's enthusiastic, yes he's enthusiastic but he can't maintain concentration. So."

"Wasn't that how this person probably got their job?"

"Probably, but absolutely useless"

"[inaudible] Presenting how wonderful she is because actually, her service was disgusting."

"Absolutely disgusting."

"Did nothing for him." (FG3 line 320).

Parents appear exasperated that when their children are provided with support, it can be inappropriate and let down the child or young person after getting their hopes up. This phenomenon was reported as *'failings of the entire system'* (FG3 line 513). The following is a quote from a parent who feels that the system is damaging children and leading parents to lose hope for their child's future:

"Once again that powers that be, they like to keep you feeling negative about everything, this is it, you get told that your son, your daughter's, gonna be living with you forever because they're never going to get the skills to leave home. And you think well, he can make a cuppa tea, of course he can leave home. I know that's a leap! [laughing] But if he can learn that, they can learn everything else. But you know in your heart of hearts that's possible, but then these people tell you and repeatedly tell you that it ain't gonna happen. So, in the end, you stop believing it! Kids actually are damaged by the system that's trying to help.... and I think it's important to give that light at the end of the tunnel." (FG3 line 367).

"Because that's what we was told, basically, you know what I mean?" (FG3 line 380).

"I felt, felt awful, you know what I mean, it's um it was like..." (FG3 line 381).

"You've resigned to the fact that [child]'s not gonna make, set the world alight – well I hope not [Humour relating to setting pasta on fire]." (FG3 line 384).

Parents questioned the competence of professionals and suggested that further training and more appropriate insight may be helpful:

"And it also comes down to the point of, how do these people get these jobs? Because what we've dealt with is people who are singularly incompetent and not fit for purpose." (FG3 line 239).

However, parents appear reflective, and the following exchange highlights that parents understand the challenges faced by professionals:

"But professionals need more... education," (FG3 line 798).

"They certainly do." (FG3 line 799).

"*And to be honest with you... it's not the persons' fault, it's a total system failure, "* (FG3 line 800).

"It is." (FG3 line 801).

"If you train someone totally wrong, they are going to be totally wrong, and never going to be different, because you not told any different," (FG3 line 803).

"Re-education." (FG3 line 806).

Further discussion led parents back to the systematic failings that they had experienced and the lack of person-centred approaches:

"They don't treat them as a person," (FG3 line 812).

"It's the system again though, not the person's fault, but we are lucky, we are here now, at the point when things are changing, it is happening." (FG3 line 813).

"It's not person-centred... its label centred...." (FG3 line 816).

Category: Child Presentation

The figure below provides an overview of the sub-themes and codes related to the category of Child Presentation for each group under primary, secondary and young adults in the table below. Child Presentation represents what parents notice about their children and how they are supported. In this theme, anxiety was a code that occurred in all three focus groups, highlighting the ongoing nature of anxiety in their children. It should be noted that the analysis aimed to generate themes that were of significance to the parents, the themes that are not highlighted in some groups do not mean that parents had no concern, rather other issues overshadowed them.

Table 10. Category: Child Presentation, Themes & Codes - Overview All Groups

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
Child's Presentation	Challenges	Anxiety		
		Communication		
		Sensory differences		
		Special Interests		
			Not recognising difficulties	
			Stress	
				Detached
				Difficulties escalated in adulthood
			Aggression	
	Coping Strategies		Own coping strategies	
			Unable to cope	
			Behaviour that challenges	
			Self-harming	
	Learning Style			Repetitive learning style
				Seeks help
				Rewards to motivate

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
				Development of social and emotional skills
				Delayed development
				Flourishing at University
				Taking time to achieve goals
				Developing life skills
				Scheming and manipulating to get own way
	Parent Support			Explicit teaching
				Actively supporting experiential learning
				Parents adapting to meet needs
				Parent over-responsiveness
				Empathy
	Professionals			Gave parents limiting beliefs about development

Category: Presentation Focus Group 1 Parents of Primary School-Aged Children

Parents talked about the child's special interests (FG1 line 73) and how these can lead to situations where the child experiences positive or negative experiences depending on the outcome of a game show (FG1 line 69) and how this was related to the child experiencing anxiety, (FG1 line 64).

*Umm Alex, is described quite perfectly, with his issues, he's on about tipping point at the moment umm the star dropping at the end, if the star doesn't drop at the end he obsesses over it and yesterday the star didn't drop and he's still talking about it today from yesterday. And er it gives him a lot of anxiety, (*FG1 line 64).

R ummm

P3 when it did drop, when he watched an episode when it did he did about a 30-second YEAHHH [raised hands in the air] and umm that's where we are. That's cos he's been talking about stars for quite a while, it's the star on the counter that's been bothering him. (FG1 line 69).

A parent who is also a practitioner discussed how surprised most people are when they learn how critical sensory differences are (FG1 line 376) and how her child's auditory senses affect her, (FG1 line 378).

I think it surprises a lot of people when you talk about it, how much it affects our young people, umm you know and how much my daughter's auditory hyposensitivity, people think that she is deaf, she's not, and she just can't pick up beginnings of sentences, so she comes in halfway. Whatever you have said in the first words she won't pick up, she just picks up the end. (FG1 line 378).

Focus group 1 'presentation' theme was mainly focused on the sensory aspects of the children.

Category; Presentation Focus Group 2 Parents of Secondary School-Aged Children

Within this theme, parents provide examples of difficulties with sensory differences disrupting daily life:

"[interrupts] my son's recently got a diagnosis and [unintelligible] disorder as well and was struggling at school if he was doing any exams he could hear the pen scratching he could hear the clock ticking, he could hear people breathing, it was liked "I'm trying to do an exam in a coffee shop Mum" it's that loud to him." (FG2 Line 131).

"It just feels like he's going to bombard himself with other stuff to sort of block it out, and then when he is not allowed on his Xbox cos it gets stopped after dinner because after dinner you are not allowed electrical in our house. But then his walking around getting all wound up and stressed, and what do you do, what do you do? You need to give him something to do otherwise he gets himself all stressed out. I can't find anything quick enough." (FG2 line 595).

Parents described children developing various coping strategies, through exerting control or 'masking' and not leaving the house unless there will be a self-perceived success:

"My son's way of coping with things is to try and control everything, he can keep in control of everything he can cope, but as soon as that control is taken away in any way shape or form he's gone, just completely, he can't cope. And if anyone challenges that, he will argue until he's red in the face, he will not, will not do anything he doesn't want to do." (FG2 line 149).

"Behaviour in that respect, no it shouldn't, no, he's never done anything like that, can get to a place, he will only leave the house if he can perform 100%. So at the moment if he can't see himself [voice is getting louder] getting through, an entire day. And doing what I call, his act, hi here's me, I'm [child]. Umm, he won't leave the house." (FG2 line 320).

Parents are also aware of the difficulties their children are having coping with life, and their strategies are no longer working:

"My son hates his life, he asked me, mom, why was I born? I'm not meant for this world. And it's heartbreaking, it's horrendous." (FG2 line 218).

"Secondary school that's where we had the meltdowns and that's when he had to literally say to me, I cannot hide it anymore Mum, I cannot hide it. And that was it, and that's when the anxiety started you know, a child nearly as big as you, in the boot of the car because he doesn't want anybody to see him, especially his peers." (FG2 line 409).

Parents discussed their children's behaviour and how this can escalate into aggression towards others, or self-injurious behaviours in a variety of settings:

"Had a maths teacher who was a PE teacher, and he's wiping the floor with her because he's so irritated he's putting himself across as really really badly behaved." (FG2 line 265).

"She flies off the handle at nothing at all, so there will be the triggers, and there will be other things, so yesterday I had a knife and fork on the table and she just [inaudible whispering] if you don't foresee it because your not umm aware that's going to happen, and you're supposed to put her out of it and get one of her coping strategies, and that can work, but I

just wasn't aware that was going to happen, and when they're having a meltdown there is no reasoning with them just let them finish." (FG2 line 287).

"I have to collect her every day because she hits other children [inaudible] err childminders, so that's a big, it's too much, and then you get your fill from her on how terrible the day's bin." (FG2 line 306)

"I went to [inaudible] [child] {inaudible] He'll smack his head on walls, He'll get things and [inaudible] himself with, and when he's in a meltdown, he doesn't care for his own safety or anybody else's safety at that point in time. He'll run into the road, he'll lie in the road, he'll hit me, rip my clothes off, throw them about. It's just…" (FG2 line 323).

While parents shared the difficulties that they and their children were experiencing, there were reports of things that were going well, for example:

"But at school now both of them will conform and behave relatively normally, but school don't pick up or help with autism." (FG2 line 308).

"You can't laugh at him, but when he's having a meltdown, you have to really try not to. Because he throws something, he throws something soft, and he throws to miss. And he is never actually trying to hurt anybody, he has hit and broken things. But he is in control. Which is actually a positive. Yay! Is positive, but we can have four, four and a half hours of opposition, defiant behaviour." (FG2 line 327).

Within the presentation theme, parents identified that sensory issues were leading to behavioural problems, child mental health problems and self-injurious behaviours, with a latent theme that problems being experienced are escalating.

Category: Presentation Focus Group 3 Parents of Young Adults

Of fundamental interest was the parent's positive or optimistic perspective, which was a theme that ran throughout the discussion. Parents compared the behaviour or presentation of their child to other young people of the same age, or themselves when they were young:

"Well, now with [child], [child] can actually take care of himself now to a fashion [laughs] he can feed himself, look after himself, run a washing machine, you know it's, a lot of the time he's just your basic 20 year old." (FG3 line 40).

"We all know what we were like when we were twenty, don't we?"[chuckling] (FG3 line 44).

"…autistic children could still be naughty, and its normal behaviour, naughtiness, and I would see it as naughty behaviour and tell them off…" (FG3 line 414).

While parents acknowledged that aspects of their child's development were delayed, they addressed this with the understanding that the development of skills would continue and parents were hopeful for the future:

"We are leaving him more and more you know what I mean?" (FG3 line 277).

"We are leaving him more and more but dream of leaving him for too long." (FG3 line 278).

Parents shared experiences of adapting their parenting to their child's learning style, recognising that the child learned through experience, and it was the parent's responsibility to teach the young person explicitly (FG3 Lines 60, 65, 70). In response to an incident involving her son setting fire to spaghetti, a parent stated:

"…That was my, take it on me, because I didn't teach him to do long pasta, I just said next time you do long pasta I'll show you, you know what I mean?" (FG3 line 65).

Parents explained how their children learnt through explicit teaching by parents, needing real-life experience and repetition to learn tasks (FG3 Lines 50; 55; 60; 66; 70). To help with skill development, parents felt that their children needed goals and rewards to motivate them to learn new skills:

"Bless him, but he's getting really good, obviously he's working for something you know what I mean?" (FG3 line 73).

One parent expressed the need for goals to be realistic so that the child is set up to achieve and not face failure:

"You have to have the edge to crack on, but it's no use saying, well you're going to NASA, and you're going to space, more like, get you're driving licence and drive off to work. Because nothing's worse than someone throwing a massively unrealistic thing at you, a license to fail, no one likes doing it." (FG3 line 571).

Another parent explained that it could take a long time for a young person to learn, and it can be like switching on a lightbulb:

"…but when they do get it [snaps fingers], it's like somebody switching a light bulb on." (FG3 line 689).

Throughout the discussion, parents referred to their children developing skills and continuing to develop, the areas of development were life-wide, ranging from the development of functional skills, social skills, and within education, (FG3 lines 40; 60; 66; 73; 78; 83; 107; 119; 277; 395; 430; 435).

This theme relates to parents discussing their child's presentation both in the present and in the past. Parents stated that after their child received a diagnosis, they changed their expectations, and this was at times, reinforced by professionals:

"Up until 13 he was brought up the same, the moment he got a label I was guilty as the next person." (FG3 line 400).

"You're told he's got autism, so you start treating him different, and then they come down and they make it worse." (FG3 line 403).

"That's with us isn't it? Because we were always told [child] wouldn't be able to do this, this or that." (FG3 line 105).

"*You get told that your son, your daughters gonna be living with you forever because they're never going to get the skills to leave home."* (FG3 line 365).

Category: Parental Concerns

The Table below provides an overview of the sub-themes and codes related to Parental Concerns' category for each group. There were no codes shared between all groups in this theme, which is likely reflective of the changes experienced across the age ranges. As previously highlighted, the themes identified in each group are those that appear significant, a group not highlighting a particular theme is not a reflection that there are no problems, rather major themes lay elsewhere.

Table 11. Theme: Parental Concerns - Overview All Groups

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
Parental Concerns	Current Concerns	Perceived parental patience		
		Understanding the child		
		Parenting siblings		
		Dual role		
		Isolation		
		Parental mood affecting child outcome		
		Parental bereavement		
				Self-harm during meltdowns
				Need parental coping strategies
				The cycle of family stress
				Parent stress
				Parent frustration

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
				Stigma
				Social comparison
	Concern for Future	Unknown future		
				Fear for the future when the parent dies
			Fear of child's death or prison in the future	
			Dependent on parents into adulthood	
			Concern for non-academic child	
	Concern about other parents	Question motives of other parents		
		Hard to reach parents		
		Less informed parents		

Category: Parental Concerns Focus Group 1 Parents of Primary School-Aged Children

Parents of primary-aged children expressed concerns about an unknown future for their child. , difficulty with or their confidence in understanding the child, their self-perceived patience and empathy, isolation, and the impact of having an autistic child on the development of siblings, (FG1 Lines 79, 80,81, 82, 84, 85, 143, 144, 443, 444, 445, 448, 505). Some parents referred to their emotional responses to the diagnosis of their child's autism as a bereavement (FG1 lines 473, 504).

"…some parents do experience some kind of bereavement." (FG1 line 473).

“There is a bit of bereavement or trauma or concern over what is going to happen in the future, yeah umm but I think it’s something that you need to be taught about.” (FG1 line 504).

An interesting point came from my / the researcher holding a dual role of both a parent and practitioner (FG1 lines 90, 93, 136) and the challenges of personally receiving perceived good support whilst working in a different local authority with families who were not being offered similar support.

*“I am sort of split in two directions really ‘cos I’m a parent and worked in autism specialism for, as a teacher, for six years and as a parent, I can see as my daughter’s been diagnosed for five years now, it wasn’t me who picked it up, by the way, I switch off when I go home [laughs], umm and I think, I also, umm work for Leicestershire, but um live in Nottinghamshire, and I think that the difference, as you say postcode lottery is important, my daughter sees a paediatrician every six months, every 3 when she goes on a new med, and this will go through her entire life. What surprises me is that here in Leicestershire, you get your diagnosis and get discharged. That’s it. You’re off. I find that really quite difficult that the personal experience I have had, with the paediatrician is very supportive, not the first one I have had, the second one because I didn’t think much of the first one, ” (*FG1 line 90).

Parents questioned the motives of other parents, and the issues raised included questioning other parents’ quest for a diagnosis for their child and other parents having a *‘victim complex’* over their child’s diagnosis, (FG1 line 226, 230, 236). Some parents reported that other parents did not want their children diagnosed (FG1 line 244) or had negative perceptions of autism (FG1 line 460).

Category: Parental Concerns Focus Group 2 Parents of Secondary School-Aged Children

Fear for the future was a concern for parents, with uncertainty about what to expect for their child's life as adults, including working and living independently (FG2 lines 245, 248, 251, 255, 510). One parent stated:

"It scares me about the future, at the moment, umm, and if he's gonna live independently and if that's ever a possibility." (FG 2 line 245).

Another said:

"I worry about work, how that's ever going to happen [inaudible] quite okay even though with the medication, and him home all the time with us, can cope with that. You know, that's not living life to the full, is it? That's not going out and finding someone to spend the rest of your life with you know? All those things you want for your children, you know?" (FG2 line 248).

These quotes highlight continuing uncertainty about their child's life as adults, leading to the self-identified fear that parents feel. Parents do not appear to be hopeful of ordinary life transitions happening in the future. It may be that the combination of lack of insight and experience of autistic adults creates a decrease in expectations. Coupled with the continuing challenges being faced by parents and children, parents may lose hope for the future, or protect themselves by not wanting to get their hopes up, for fear of them being dashed.

The level of fear and distress experienced by some parents is highlighted in the following comment:

"[interrupts] if my son carries on, he's either going to end up in prison or dead, you got to help me, that's not a solution [choked up voice]" (FG2 line 361) [comment in response to researcher discussing parents firefighting crises].

Despite the concerns raised by parents and having tried strategies that have not been effective, some continued to show a willingness to try new things:

"*My son hates his life, he's asked me, 'Mum why was I born?' I'm not meant for this world. And it's heartbreaking, it's horrendous, so if you can offer anything that's gonna make him feel more a part of this world and that his meant to be here, then I'm willing to.*

"I've dedicated, my whole entire life to trying to find help for [son], I've got so many books on so many much and read them all and tried so many worksheets. And I've gone over Birmingham to their autism place and um ABA and mental health and tried everything to help

him. Everything I've tried so far, it's not worked, but I'm more than willing to try everything and anything, so." (FG2 Line 218).

Focus group 2, despite continued challenges, and concern for the future, with little insight into what to expect in the future, parents appeared to be open to new strategies to help.

Category: Parental Concerns Focus Group 3 Parents of Young Adults

This theme represents a discussion about the stress and anxiety of parents and their children. Parents described these experiences of their children as 'meltdowns', and these could lead to a risk of harm:

"…after who knows how many years of meltdowns, and meltdowns, meltdowns and meltdowns, and meltdowns…(FG3 line 466).

"Because he's thrashing about on some occasions and I had to stop him from hurting himself," (FG3 line 476).

Most discussions within this theme were related to anxiety and stress that parents experienced:

"I think the older you've got, the more we've sort of educated ourselves and are better with the coping strategies. To the outside world it's extremely stressful, but to us, it's every day." (FG3 line 692).

"You've got used to working or being at that level of stress, anxiety and that, that it becomes the norm," (FG3 line 697).

"*It's... you, you have extra stress,"* (FG3 line 733).

One parent was aware that his son was creating stress for his enjoyment:

"*But the stress and anxiety, sometimes if they see that... I mean... [child] sometimes gets a kick out of it,"* (FG3 line 828).

Parents were aware of the family stress cycle, and the need to do something to break the cycle:

"…if you don't react and walk off biting your lip, then you're going to break that stress and anxiety circle," (FG3 line 835)

A parent commented about the lying and manipulation that their children used to either avoid expectations or to create stress within the family:

“He’s very good at manipulating things, and scheming things to his own way.” (FG3 line 397).

Parents stated that after their child received a diagnosis, they changed their expectations, and this was at times, reinforced by professionals:

“Up until 13 he was brought up the same, the moment he got a label I was guilty as the next person.” (FG3 line 400).

“You’re told his got autism, so you start treating him different, and then they come down and they make it worse.” (FG3 line 403).

“That’s with us isn’t it? Because we were always told [child] wouldn’t be able to do this, this or that.” (FG3 line 105)

“*You get told that your son, your daughters gonna be living with you forever because they’re never going to get the skills to leave home.”* (FG3 line 365)

There was a concern for the future, questioning what would happen to the child when the parent is gone, (FG3 line 389).

Focus Group 3 experienced continued meltdowns and recognised when these were avoidance strategies. The continued stress parents experience was discussed. Future fears were related to what would happen to the child when the parents were dead.

Category: Parental Needs

The figure below provides an overview of the themes and codes related to each group's category, ‘Parental Needs’. There were no codes shared between all groups in this theme, which is likely reflective of the changes experienced across the age ranges.

Table 12. Theme: Parental Needs

<table>
<tr><td colspan="2"></td><td colspan="3">Sub-group</td></tr>
<tr><td>Category</td><td>Themes</td><td>Primary</td><td>Secondary</td><td>Young Adult</td></tr>
<tr><td rowspan="11">Parental Needs</td><td rowspan="5">External Support</td><td colspan="2">Guidance</td><td rowspan="3"></td></tr>
<tr><td colspan="2">Advice</td></tr>
<tr><td colspan="2">Peer Support</td></tr>
<tr><td>Information</td><td rowspan="2"></td><td rowspan="3"></td></tr>
<tr><td>Trusted Information</td></tr>
<tr><td rowspan="4">Challenges</td><td colspan="2">Anxiety</td></tr>
<tr><td rowspan="5"></td><td colspan="2">Stress</td></tr>
<tr><td>Over-involvement</td><td></td></tr>
<tr><td>Own experiences of school</td><td></td></tr>
<tr><td rowspan="2">Parental Coping Strategies</td><td rowspan="2"></td><td>Humour</td></tr>
<tr><td>Remove self from conflict</td></tr>
</table>

Category: Parental Needs Focus Group 1 Parents of Primary School-Aged Children

Parents stated that they needed information, advice and guidance that they could access together, and this joint learning would lead to enhanced value and outcomes. Parental quest for knowledge and understanding was suggested to lead to some parents *'grasping at straws'* (FG1 lines 119, 120, 125, 182, 183, 184, 198, 202) and placed a high value on peer support (FG1 lines 132, 134, 254, 260).

"I think meeting other people in that support and knowing what you are doing is OK." (FG1 line 118).

Whilst parents suggested that they felt isolated and alone (FG1 lines 116, 253), there was a reference to personal anxiety and how this could hinder course attendance. A parent stated that leaving the child with another caregiver raises questions as to whether the caregiver could cope with the child. Regarding their child's behaviour, parents highlighted that there might be anxieties about attending a new group and what other people would think about them (FG1 lines 278).

"*You wonder can I manage to leave my child with my husband when I go along to this, so there is that anxiety of how you will present, with your children, um, with autism that's a big thing. A lot in our past we've not done things because we have been worried about my son, what will they do, what will they think, cos I know how he will behave so that I think can be a big barrier." (*FG1 line 275).

Category: Parental Needs Focus Group 2 Parents of Secondary School-Aged Children

There was an acknowledgement of parental anxiety, anger, stress and overload (FG2 lines 312, 321, 344, 346, 348, 350), with occasions (FG2 line 312, 321, 362) during the discussion of parents raising voices or banging the table:

"Which means they have to provide more staff which is more money and they can't and won't do it! [bangs on the table as she speaks angrily]." (FG2 line 310)

> *"Don't know what's going to be, so*
>
> *I'm automatically anxious."* (FG2 line 344).

Parents discussed the cycle of parental and child anxiety, the challenges of not knowing how their child will cope and the subsequent impact on daily life:

> "*You wake up anxious, and its* [inaudiable]" (FG2 line 348).

"What child I'm going to get that day, how's he going to cope that day [voice getting louder] *or I think I see something change"* (FG2 line 350).

“and it can be minute to minute and hour to hour and second to second.” (FG2 line 352).

The last comment highlights that some parents may be reacting to their children’s mood or behaviour rather than proactively using strategies to manage anxiety and escalated emotions. It is intended that the proposed programme will offer a range of strategies for parents to use with their children to manage their emotions and behavioural responses.

Whilst discussing rumination and retraining of thoughts of children, one parent suggested that parents need to retrain theirs first (FG2 line 481), another stated that she was depressed about the future (FG2 line 510). One explained that her fears were leading her to become over-protective, and her children were not flourishing as a result:

“I think because I’ve had less support I’ve become very, very overprotective over my son, and both my boys are terrible at saying I’m overprotective, which then means they’re not flourishing as well as they should because I’m too scared to let them do things.” (FG2 line 702).

Category: Parental Needs Focus Group 3 Parents of Young Adults

This category represents a discussion about the stress and anxiety of parents and their children. Parents described these experiences of their children as ‘meltdowns’, and these could lead to a risk of harm:

“…after who knows how many years of meltdowns, and meltdowns, meltdowns and meltdowns, and meltdowns…(FG3 line 466).

“Because he’s thrashing about on some occasions and I had to stop him from hurting himself.” (FG3 line 476).

Most discussions within this theme were related to anxiety and stress that parents experienced:

“I think the older you’ve got, the more we’ve sort of educated ourselves and are better with the coping strategies. To the outside world it's extremely stressful, but to us, it's every day.” (FG3 line 692).

“You’ve got used to working or being at that level of stress, anxiety and that, that it becomes the norm.” (FG3 line 697).

“*It’s... you, you have extra stress.”* (FG3 line 733).

Category: Positive Perception of Child and Autism

The Table below provides an overview of the sub-themes and codes related to the category of Positive Perception for each group. There were no codes shared between all groups in this theme, which is again likely reflective of the changes experienced across the age ranges.

Table 13. Category: Positive Perception Over-view All Groups

<table>
<tr><td colspan="2"></td><td colspan="3">Sub-group</td></tr>
<tr><td>Category</td><td>Themes</td><td>Primary</td><td>Secondary</td><td>Young Adult</td></tr>
<tr><td rowspan="11">Positive Perception</td><td rowspan="5">Perceived Strengths from Parent</td><td colspan="2">Autism strengths</td><td rowspan="3"></td></tr>
<tr><td colspan="2">Balance strengths and weaknesses</td></tr>
<tr><td>Prepare the child for diagnosis</td><td rowspan="6"></td></tr>
<tr><td>Need to parent differently</td></tr>
<tr><td rowspan="2"></td><td>Shift in perception</td></tr>
<tr><td>The benefit of de-escalation techniques</td></tr>
<tr><td rowspan="4">Challenging Externally</td><td>Challenge perceptions of others</td><td rowspan="5"></td></tr>
<tr><td rowspan="4">Understand the impact of negative</td></tr>
<tr><td rowspan="4"></td><td>Need for hope</td></tr>
<tr><td>Need for expectations</td></tr>
<tr><td>Normalising</td><td rowspan="2"></td><td>Ordinary behaviour in relation to others</td></tr>
</table>

		Sub-group		
Category	Themes	Primary	Secondary	Young Adult
				Normalising difficulties

Category: Positive Perception Focus Group 1 Parents of Primary School-Aged Children

Parents were challenging the perceived ‘negative’ perceptions of others towards autism, including those of professionals. They expressed that they felt that autism was not negative and that more training was needed to combat others' negative perceptions of autism (FG1 lines 434; 436; 455; 458; 459). Concerning the programme feedback, there was a strong desire to include positive adult stories to decrease the uncertainty of the future and balance interventions on strengths and weaknesses. This theme was recurrent throughout the focus group discussion and highlights the parent's desire to create a balance of support and positive attitudes surrounding their children.

[Regarding a negative comment from a professional] *“That’s negativity. That’s straight on. Negative. It didn’t bother me his autism is what makes him wicked.“* (FG1 line 458).

“but that’s what I’m saying like, I don’t agree with it. She’s the one coming to the house, supposed to be helping parents and in one sentence it’s like she pissed me off.” [tone of voice heightens] (FG1 line 461).

Category: Positive Perception Focus Group 2 Parents of Secondary School-Aged Children

Parents expressed that there is a need for a positive perception of their children and valued the focus of the proposed programme:

"There is nothing else out there when I saw it on FaceBook [recruitment post for the focus groups]*, I was jumping up and down with joy because it is what's needed, is something, somewhere to go after diagnosis, and it needs to be on the positive side. Not a punishment side, punish this, punish that, it will get into their head sooner – it doesn't, it brings them down more, damages self-esteem, their confidence and makes them hate themselves. After their diagnosis, it needs to be a positive thing for them, and this is the first time I've heard of actually seeing something on a positive side."* (FG2 line 231).

"I can create [inaudible] for my son and make him feel good about himself, and his diagnosis and who he is, and yer, it's going to be brilliant." (FG2 line 254).

Parents were also keen to share examples of their focus on what was going well for their children and how they were framing their thinking and supporting children to focus on positive aspects of life:

"My son, I don't say to him, how did your day go? I say to him what went well today?" (FG2 line 571).

"Can I just say that [child] does because [child] is IT mad and is brilliant at it." (FG2 line 634).

"*Very good at that.* [Re: discussion on engagement," (FG2 line 674).

Category: Positive Perception Focus Group 3 Parents of Young Adults

The parent's positive perspective was a theme that ran throughout the discussion. Parents compared the behaviour or presentation of their child concerning other young people of the same age, or themselves when they were young:

"Well, now with [child], [child] can actually take care of himself now to a fashion [laughs] he can feed himself, look after himself, run a washing machine, you know it's, a lot of the time he's just your basic 20 year old." (FG3 Line 40)

"We all know what we were like when we were twenty don't we?"[chuckling] (FG3 line 44).

"…autistic children could still be naughty, and its normal behaviour, naughtiness, and I would see it as naughty behaviour and tell them off…" (FG3 line 414).

While parents acknowledged that aspects of their child's development are delayed, they addressed this with balance and understanding that the development of skills would continue and parents were hopeful for the future:

"And you think well, he can make a cuppa tea, of course, he can leave home. I know that's a leap! [laughing] But if he can learn that they can learn everything else." (FG3 Line 367).

One parent discussed his changing perspective on autism:

*"I was hoping, one day they will have a magic pill that will take it away and one day they will wake up and be...." (*FG3 Line 704) "*But now I would never, never."* (FG3 line 707).

Throughout the discussion, parents referred to their children developing skills and continuing to develop, the areas of development were life-wide, ranging from the development of functional skills, social skills and within education (FG3 lines 40; 60; 66; 73; 78; 83; 107; 119; 277; 395; 430; 435).

This theme relates to strategies that parents have said they have adopted to cope or use during discussions. Parents displayed humour during discussions, for example, group laughter throughout the transcription (FG3 lines 39; 82; 128; 130; 132; 161; 197;219; 242; 262; 378; 386; 388; 412) and comments in response to the discussion, for example, after the researcher explained the delay in functional skill development, the group chuckled, and a parent responded dryly:

> "*Well spotted."* (FG3 line 25).

The use of humour continued, including sarcasm during a discussion about inappropriate or misdirected support. The humour instances may be due to feeling comfortable having known the researcher or using humour to decrease negativity associated with aspects of discussion such as inadequate support and delayed development.

Other strategies parents report is to remove themselves from conflict:

"It is the best one, some you know, do other things, some people just get out of the firing line to diffuse the situation." (FG3 line 672).

Category: Education

The figure below provides an overview of the sub-themes and codes related to Education for each group. There were no codes shared between all groups in this theme, which is likely reflective of the changes experienced across the age ranges.

Table 14. Category: Education Overview All Groups

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
Education	Challenges with provision	School exclusions due to School lack of understanding of sensory needs		
			Out of school	
			Inappropriate for child	
			Needs not being met	
			Teacher training questioned	
			Inappropriate teacher comments or behaviour towards the child	
			Two teachers' physical restraint of a child	
			Teacher inflexible approach	
				Attending college

		Group Codes		
Category	Themes	Primary	Secondary	Young Adult
				Flourishing at university
				Previous exclusions
	System		Lack of reasonable adjustment in exams	
			Need insider knowledge to get needs met	

Category: Education Focus Group 1 Parents of Primary School-Aged Children

One parent reported that the schools were excluding children due to their behaviours when the children's sensory differences or needs were not being supported:

"The schools are excluding children as well, based on the behaviour based on how they are having difficulty with the noise or the screens or whatever it is with school and umm, err, they might be aware the children have, well they are not statements anymore, but they may be aware but not patient or tolerant enough of how that may affect them, so education is key to this, [deep breath intake] education is the key I think." (FG1 Line 405).

Category: Education Focus Group 2 Parents of Secondary School-Aged Children

Parents reported challenges with the child's educational provision, with some children being 'out of school' for significant amounts of time. The quote below reflects this:

"[unintelligible] that we input what we got to somebody that's close to you, and you thought, oh brilliant, because my child wasn't diagnosed very early, so has got all those things really bad and didn't attend school for the last two years, and [unintelligible mumbling] had to do exams [mumbling] I had to get him to participate, and I would imagine that's the same for quite a few." (FG2 line 78).

"[interrupts] My kid has not gone to school for five years, hopefully, will be going to a special school in September, he's been taught at home [unintelligible] first year he had 60% attendance, 2nd year maybe zero. Post diagnosis, after that diagnosis, first year, failed everything [unintelligible] with autism outreach as well, so... hopefully next year." (FG2 line 81).

The parent describes escalating difficulty for the child, with decreased attendance and achievement over time, resulting in no school placement for five years. Another parent explained that escalating difficulties resulted in the child being out of school for six months and the reason that she was able to return him to school education was that she taught at the new school:

"Umm so for two years they really struggled with him, and told me, nothing, I didn't realise there was no system for contacting home. [inaudible] Misbehaves and gets detention, contacts home, nobody knew he was missing at the school that he was, so he went back in complete meltdown, and missed school for six months altogether, couldn't get him in anywhere. And he was fourteen, I had to go to work, dad's very autistic and [inaudible] for three years, because he's completely mad, an umm so there's nothing I can do but stay home. And eventually got him in year nine at the school where I teach because there were no other options. If I wasn't in education, I wouldn't have got either of my kids to where they are now." (FG2 line 267).

The same parent described difficulties with her autistic daughter's school placement and trying to get her an appropriate placement. Working in the education sector, for her, is the key to getting the right placement for the child:

"She's going to [inaudible] academy after the weekend, [inaudible] autistic [inaudible] she's going to repeat year six in the autumn term, starting secondary, emm but again, if I didn't work in education, what would I have known to get any of these, me and to push and push and hammer and hammer, [inaudible, someone coughing over] miles away, to Cedars

Academy which is a massive mainstream academy with a speech and language in it, she's not got speech and language problems, umm this is where they want to send her because they don't want to pay for a specialist autistic." (FG2 line 300).

As well as parents discussing educational placements generally, they also highlighted specific problems relating to inappropriate support or treatment of their children within the educational setting:

"I'm having a problem with my son's school at the moment because his teacher called him stupid." (FG2 line 726).

"School for forty-five minutes, because he just couldn't cope, and he was attacking all the teachers and pupils who actually had to evacuate the classroom. And one teacher had to sit on him and the other had to hold his arms down." (FG2 line 316).

Category: Education Focus Group 3 Parents of Young Adults

In this area, one parent highlighted how, despite not being able to read at 10yrs and having behavioural problems, her son is now at University, and her second autistic son has transitioned to college:

"I mean, my oldest son of my two boys whom you know very well, they did half a day of school because he was uncontrollable, and he couldn't read up to age ten! And now he's got a first in his first year of uni.... and he's 21, so it can, can happen." (FG3 line 118).

"He's now at, his, his got to a level where we can actually, he will go to college. So we thought he would go to Herewood, and said yeah that's not a problem, and at school, they said he'd reached the level, cos there's kids at school that haven't." (FG3 line 197).

This parent reflected on the challenges of experiencing a change in the early years, and she described his behaviour in response to a change of teacher:

"and he was like wild around the classroom, running wild because it's different." (FG3 line 502).

"and when his teacher came back he walked in into school, and he was like a lion, and when he has seen his teacher she went, now, now [child's name], I'm back what do we do? And it was like a light went on and she said he was better behaved than most the normal kids in the class." (FG3 line 514).

Discussion

The following section will summarise the main findings from each focus group in turn and follow a general discussion that contextualises the analysis concerning the current literature (Braun & Clarke, n.d., Braun & Clarke 2006).

Parents of Primary School-Aged Children

Parents expressed a need for knowledge and appropriate support both socially, from family, peers and professionals. This was reflected in the parents staying ‘on the topic’ more than the other two groups and providing more suggestions for the programme's content and delivery. Parents may be experiencing a ‘void’, and they lack a clear picture of what to expect in the future, for both themselves and their child/ren, which was addressed during the discussions. While parents report not knowing what the future holds and the challenges they face, they are clear in their desire for a balanced approach. They suggest a need to provide the opportunity to develop their children’s strengths and attributes and strategies to support the children’s difficulties.

Whilst parents need support, advice and guidance, with insight into what to expect in the future, they also appear to be self-determined and wish to support their children’s development within their family units, including their extended family.

Many barriers were discussed regarding programme access and presentation, with a desire for online resources and support to aid the implementation of the strategies at home.

To summarise, parents in this focus group could be described as enthusiastically seeking knowledge and expert support to understand and support their child. The discussion centred around issues regarding diagnosis and the need for timely diagnosis and interventions and challenging the negative perceptions of autism. Parents reported several barriers to attendance and expressed a desire for full family access and online support.

Discussion Focus Group 2 Parents of Secondary School-Aged Children

Parents described significant difficulties that they and their children were currently experiencing or had experienced previously. There is an emerging picture of increasing life-wide challenges the children face with increasing behavioural difficulties, stress and anxiety. The parents spoke with frustration and desperation and appeared to be experiencing escalated emotions, resulting in raised voices and banging on the table. Parents reported being let down by a lack of support or inappropriate support for their children in CAMHS and educational settings. The children represented in this group are being exposed to multiple co-morbid diagnoses to account for their presentation and polypharmacy in an attempt to

alter their symptoms. Children from this group were reported to be experiencing escalating difficulties within educational settings, resulting in behavioural problems, exclusions and leaving placements. These findings mirror those from the review of literature on autism in Chapter 1 and Autistic Development Theory in Chapter 2.

The findings indicate that parents want and need family support based on developing strengths and helping children cope with their escalating difficulties.

Discussion: Focus Group 3 Parents of Young Adults

Parents in this group appeared to be hopeful about the future. Parents were reflective of their journeys and described the challenges they faced in the past and present. Parents could describe and identify their child's continued learning and development and their role within this. Parents appeared to be realistic about their child's developmental delays and that with their support, their child would continue to develop skills.

Parents normalised their children, comparing them to typical young people and appeared accepting that their lives are different from other families. There appeared to be a hopeful and positive attitude from the parents towards the future.

The parents displayed distrust and hostility towards some of the professionals they had encountered in the past. It was the parents' opinion that professionals have held limiting beliefs about their children's development and futures, impacting the parent's beliefs about their children's capabilities. They did acknowledge that the failures may be due to the professional training and the system, holding the opinion that more training of professionals and systematic changes would be helpful.

Generally, the parents seem accepting of their continued journey with their child and seem to just get on with what they perceive needs to be done.

General Discussion

The three focus groups provided rich and detailed insights into the experiences of UK children and young autistic adults, as reported by a sample of 12 parent participants. While these findings are specific to the participants and may not represent all families, they align with the evolving experiences of parents over time.

Parent focus and experiences appear to change over time. The children's reported experiences and challenges also change over time and reflect the literature. The focus of parents' attention changed with the child's age, to summarise, parents of younger, primary-aged children appear to 'need to know'; they seek information, advice, guidance and a vision for the future. Parents of older, secondary-aged children, appear more overwhelmed,

stressed, frustrated and let down by lack of understanding and support from others. Some of the adolescent children face multiple co-morbid diagnoses and polypharmacy. Parents of adults were aware of the differences in learning and identified these, alongside their child's continued development and their continuing role within it. The parents of young adults seem more at peace with their circumstances, and despite continued stress, they appear to be using humour to deal with it and appear to be hopeful for the future.

These insights mirror longitudinal research that has found that parents' coping strategies changed over time, from initial service provision, isolation and family support, to using more philosophical and emotion-focused coping strategies (D. E. Gray & Gray, 2006). Many parents report a period of intense emotional adjustment following their child's diagnosis, often described in terms of grief, shock, guilt, and even mourning the 'expected child' (Fernández-Alcántara et al., 2016; Gentles et al., 2020). This emotional turmoil is compounded by delays in diagnosis, which can cause frustration and feelings of helplessness (Crane et al., 2016). Yet, once a diagnosis is secured, it can also bring relief and validation, allowing families to access services and better understand their child.

Parents from all groups discussed issues around diagnosis, and the parents of young adults expressed the importance of early diagnosis and recognised that a child's presentation had led to difficulties in diagnosing him. Parents expressed dissatisfaction in all focus groups. Using the Millennium Cohort Study data, a recent study has explored the issues that may lead to delayed diagnosis (Hosozawa et al., 2020). The authors of the report found that 79% of children were diagnosed after entering school, with 28% not receiving a diagnosis until secondary school; however, 75% of these children had been highlighted to have socio-communication issues at five years. It has been reported that factors that may contribute to late diagnosis are the child having typical intelligence, little or no parental concerns over the child's development and poverty (Hosozawa et al., 2020). A study of 1047 parents found that parents usually wait for a year after noticing signs of autism to seek professional help. It was also found that there was an average three-and-a-half-year delay between seeking support and a diagnosis being given and this led to parental dissatisfaction (Crane, Chester, Goddard, Henry, & Hill, 2016).

The parents of primary and secondary-aged children recognised the need to access post-diagnostic support. The PACT intervention (Parent Mediated communication-focused treatment) (J. Green et al., 2010) found that outcomes were reduced autism symptoms compared to controls, and positive effect for synchronous parent responses, child initiations with the caregiver and parent/child joint attention. These findings support the parent's opinions that early intervention is necessary for children and families.

Parents highlighted a lack of support and a ‘post-code lottery’ of availability, or when provided, the support was not always appropriate. Inconsistent support is recognised as a problem by the National Autism Project, alongside evidence-based practice gaps (Lemmi, Knapp & Ragan, 2017). Parents in the focus groups felt that support was imbalanced and more needed to be done to address this and also focus on the child’s strengths. Many of the issues discussed in this section have been highlighted by a lack of empirical-based interventions and a lack of development of strengths; this is reflected by researchers who advocate for strengths-based education (Mottron, 2017).

Some parents reported that some professionals showed limiting beliefs and negativity about the prospect of development and independent adult life. Some reported that these had influenced their own beliefs about their child’s potential and visions for their future life and had changed their expectations and parenting approach. As discussed in Chapter 1, these limiting beliefs can not only lead to misunderstandings, such as the belief that autistic children are not able to lie, but also limit children’s access to experiential learning and opportunities to develop and reach their potential. Parents talked about a need for increased training for professionals to ensure that they had a solid understanding of autism to inform their practice. A 2012 study from Spain found that teachers were usually positively engaged with their autistic pupils. However, teacher attitude was influenced by how much experience they had with the particular child, whether the school was mainstream or special, and whether it was part of an autism network. Special schools were associated with more positive attitudes. The authors concluded that the greater need for mainstream teachers was information, regardless of an. autism network, and likely because the inclusion of autistic children in mainstream settings is challenging (Rodríguez, Saldaña, & Moreno, 2012).

Parents described a process that they go through after their child’s diagnosis. They were reflecting on the changing nature of parental focus and emotions over time. It could be argued that parents may be experiencing a transition of change, and the transition brings different stages and emotions during the process. Complex emotions were found in a study of parents whose child had received a diagnosis of autism (Fernańdez-Alcántara et al., r2016). The authors identified that the core category was strong feelings of grief and loss of their child. This was linked to negation, shock, fear, guilt, sadness and anger. They identified that parents need to make an effort to deal with their perceived loss and emotions (Fernańdez-Alcántara et al., 2016). These are similar findings to those of Gentles et al _2020), who recommend that interventions address the grief that parents are experiencing. To support families and enable parents to go through the process of change more quickly, the programme should focus on this and help them navigate their transition effectively. This

could lead to enhanced outcomes and more effective implementation of the strategies included in the programme

Researcher Reflections

An essential element of this work is reflecting on my experiences as a researcher. Recruiting participants was challenging. Large numbers of emails received were seeking further information, usually with numerous follow-up emails to clarify information. Of these, only 16 completed the participation forms, and only 12 participants attended on the day. Parents of young adults were tough to engage, with the only participants attending being previously known. This could be a potential source of bias, and I managed myself by using the materials to ensure that the focus groups' stages were adhered to diligently and reminded the parents that the role I was in was researcher rather than a practitioner.

It may be that parents of young adults distrust researchers, and this led to the lack of engagement from this group. Alternatively, parents may not be as focused on autism, life may be going well, and they are no longer actively involved in the autistic community, as they are more at peace with their circumstances, as were those in the focus group.

Regarding facilitating the groups, the groups became emotive, with some parents crying (groups 2 and 3) and some participants becoming angry and displaying escalated emotions. It was a difficult balancing act of giving parents the time, space and empathy to discuss their pertinent issues and remain focused on the research questions. This was easier to achieve in groups 1 and 3 than in group 2 who were facing numerous challenges.

The issues of trust, difficulty with recruitment and dealing with raw emotions are essential issues to consider when designing research projects involving families. During discussions, parents needed to be responded to with care, empathy, and respect when they became distressed. Researcher judgment is crucial in interpreting how to respond and have the flexibility to take breaks to help parents de-escalate their emotions when needed.

Strengths and Limitations of the Research

Existing Literature Aligning With This Study

The findings from this study aligns with those of other studies. Studies consistently highlight difficulties families face in accessing appropriate and timely support. These include long waiting times, post-diagnostic support gaps and inconsistencies (Lemmi, Knapp & Ragan, 2017). Many families encounter professionals who may lack autism-specific knowledge, which can further contribute to frustration and mistrust (Rodríguez et al., 2012). Participants'

accounts of delayed diagnosis and dissatisfaction echo Crane et al. (2016) and Hosozawa et al. (2020), highlighting that despite early concerns, formal recognition often comes too late.

Gray and Gray (2006) found that families shift from problem-focused coping strategies early on (e.g., seeking services) toward more emotion-focused or philosophical coping in the long-term. This may include acceptance, humour, reframing experiences positively, and finding meaning in parenting an autistic child.

There is also a growing interest in the strengths-based approach, with many parents recognizing their child's unique talents, interests, and ways of being (Mottron, 2017). Parents often become advocates—not only for their child but also for systemic change—pushing for inclusion, tailored education, and public awareness.

Distinctive Contributions of This Study

This study has offered a lifespan perspective, adding nuance by showing how parental focus changes with the child's age, from seeking clarity and guidance in the early years to grappling with systemic failures in adolescence, and then toward cautious optimism and advocacy in young adulthood.

The role of humour and hope in later years, while some studies note philosophical coping, the finding that parents of young adults often use humour and appear more "at peace" is particularly heartening and adds a positive dimension not often foregrounded in the literature.

The study highlighted a desire for strengths-based, tailored programmes: While previous literature advocates for strengths-based education and parenting (e.g., Mottron, 2017), this study shows real-time parental appetite for such programmes, offering a strong rationale for interventions grounded in positive psychology.

One of this research's strengths is that it provides a qualitative insight into families and autistic children's experiences. It also provided parents with the opportunity to feedback on the proposed programme rationale and share ideas for content and delivery. The Autism Dividend (Lemmi et al., 2017) calls for research to involve the community, as do other researchers who are members of the autistic community (Milton, 2014), and this research meets this agenda. Being a parent of an autistic young adult helped establish engagement with parents in the groups. It helped gain the participants' trust by using words such as 'we' and 'our', and interacting as a peer *and* researcher, rather than a researcher.

One limitation is that the participant numbers were low, with only twelve over the three groups. A further limitation is that focus groups provide a ‘combined local perspective’ (Grudens-Schuck et al., 2004 p.3), parents lived in 3 counties in the Midlands in the UK; therefore findings represent a local perspective and should not be assumed to represent the experiences, challenges and needs of other families. Thematic Analysis is subjective, the meanings are ‘context-bound, positioned and situated’ (Braun & Clarke, 2019 p 7.), it seeks not to uncover the truth, but a story in a context. The patterns of shared meaning from parents of autistic children have provided insight into the highs and lows, strengths and challenges, and hopes and fears, that, through the process of analysis, have created their story.

Next Steps

As previously discussed, the programme design will be informed by the literature review, Autistic Development Theory and insights gained from the focus groups. The focus groups have provided valuable and rich insight into the needs of children and their families. Parents were highly supportive of the proposed programme and made helpful suggestions regarding the course's content and delivery as well as highlighting potential barriers to access. These suggestions and insights will be used to inform the programme's content and delivery. Further insights into parents’ and autistic children's needs have been gained through the analysis of the discussions, and these insights will also be used to inform the content of the programme.

Conclusion

This chapter has described a qualitative research project seeking insight from parents of autistic children in focus groups regarding the rationale and proposed content of a positive psychology parenting programme. The intention was to undertake a participatory project in which to seek the parent’s ideas regarding programme content and delivery. The focus groups aimed to seek an understanding of a primary question and a secondary question. The primary question was feedback on the proposed programme, whereby most feedback was attained from FG1, parents of primary-aged children. This could be because they are still seeking knowledge and understanding about their children and hold greater investment in the programme. The second question, what were their experiences, provided valuable insight into parent's and children's needs and will be valuable when used in the development of the intervention.

The following chapter will describe the development of the components for the programme's content. The chapter utilises insights from the focus groups and themes that were generated to develop components for an intervention for autistic children. The components are also

informed by the review of the literature, Autistic Development Theory and Positive Psychology theory and practice.

CHAPTER SIX

IDENTIFYING COMPONENTS FOR A DEVELOPMENT AND WELL-BEING INTERVENTION

Introduction

The review of the literature and the focus groups responses and feedback highlighted that children and young people face escalating difficulties and appear to be more vulnerable to mental health problems than their non-autistic peers (Gordon-Lipkin, Marvin, Law, & Lipkin, 2018; Gotham, Brunwasser, & Lord, 2015). This thesis has also highlighted that autistic children may face a range of outcomes, from optimal, where they no longer meet the diagnostic criteria, to those who have a lifetime of support and potential mental health problems (Linden et al., 2023; Robison, 2019). It has also highlighted that identifying autistic children can be a drawn-out process, with an average wait of three and a half years from parents initially raising concerns (Wieckowski, Zuckerman, Broder-Fingert, & Robins, 2022, Crane et al., 2016). The delays in diagnosis bring a further challenge regarding current interventions, as most are focused on younger children (Fuller & Kaiser, 2020). Delays in diagnosis may lead to children not meeting eligibility criteria, isolating families from potential support. This indicates that there may be a need for interventions that are less age-dependent so all families whose children receive a diagnosis of autism can access support.

The theories offered in this thesis have proposed a potential explanation of what autism is and why it may occur, based on evidence that is currently available. Together, these theories propose a developmental picture of autism as an adapted phenotype. While adaptive to our ancestors during times of environmental instability, it is proposed that it may become maladaptive in the modern world and potentially cause a myriad of difficulties for autistic individuals. Understanding autistic children from this unique strengths-based perspective may be more helpful for parents and professionals who seek to support them to reach their potential.

The factors outlined above highlight the need for a novel intervention designed specifically for parents of autistic children. Pickles et al (2016) argue that parent-mediated interventions have demonstrated long-term effectiveness in reducing autism-related challenges for children. While a meta-analysis found that clinicians observed improvements in core symptoms following such interventions, these changes were not consistently reflected in parental reports (Conrad et al., 2021). Notably, existing interventions tend to focus primarily on younger children. There is a clear need for an approach that supports parents across the broader developmental span, from early childhood through to

adolescence, ensuring that families may access meaningful support at whatever age the child receives a diagnosis.

The intervention discussed here was developed before the publication of the UK Medical Research Council and the National Institute for Health Research's joint guidance on the development and evaluation of complex interventions (Skivington et al., 2021b). Nevertheless, the principles underpinning the guidance align closely with the work undertaken in this study. As such, the framework will be used to guide the discussion in this chapter. This chapter aims to explore the various factors that inform the design of the intervention described in detail in Chapter 8.

Context of the Complex Intervention

Skivington et al (2021b) state that the effects of a complex intervention may be dependent upon context and multiple factors may impact the context. Importantly, it is said that interventions may alter the contexts in which they are implemented by creating responses from others or changing behavioural norms or risk exposure. Context is said to be dynamic and multi-dimensional, and the dimensions include physical, spatial, organisational, social cultural, political and economic of the healthcare, health systems or public health contexts. It is also reported that complex interventions that are effective in some settings may be ineffective or even harmful in others, (Skivington et al., 2021a).

As previously discussed, historically, there have been divisions between research and neurodiversity advocates. There are calls for a balanced view of neurodiversity, that considers strengths and weaknesses, with some differences creating either an inherent or environmental disadvantage that could benefit from targeted intervention (Leadbitter, Buckle, Ellis, & Dekker, 2021). There are three stated implications for intervention. The first, oppose attempts to cure or 'normalise' autistic children. Second, the aim is to improve the 'goodness of fit' between the child and their physical or socio-emotional environment. Interventions that encourage and give opportunities for physical, sensory and emotional regulation are welcomed. The third implication concerns the balance of supporting a child's development without attempting to change the essence of the person, (Leadbitter et al., 2021).

Taking these calls into account, a strengths-based approach and providing tools and strategies to decrease stress, anxiety and children's well-being should be welcomed by the autistic community.

Programme Theory

Programme theory should describe how an intervention is expected to lead to its effects and under what conditions, as well as highlight the key components, how they interact, the

mechanisms of the intervention and the features of the context that may influence the mechanisms (Skivington et al., 2021a). This section will focus on the programme theory.

Most parent-mediated interventions seek to work on the perceived deficits of autistic children and autism symptomology (Rojas-Torres, Alonso-Esteban, & Alcantud-Marín, 2020). The focus group theme Feedback for the Proposed Programme, sub-theme Content, highlighted a Positive Response to the Programme, a Need for a Positive Perception of Children and to Develop Strengths. This is indicative that parents may welcome a strengths-based intervention and engage with the programme.

This stage of developing a complex intervention is either developing a new intervention or adapting an existing intervention for a new context, based on research evidence and theory of the problem. This chapter will now discuss the development of the components for a strengths-based intervention for autistic children and their families. They have been informed by the theories offered in this thesis, themes formed by focus groups, the literature review and positive psychology theories and practice. The overview of each component will discuss the theory of how the component will be effective.

Positive Psychology Components

As discussed in a previous chapter, Lyubomirsky and Layous (2013) offer a positive-activity model in which positive activities, the person, and person-activity fit, each impact the outcomes the positive activities have on well-being. They suggest that relatively simple changes to behaviours and thoughts may increase happiness; however, activities rely upon person-activity fit. Positive activities lead to increased positive emotions, thoughts, behaviours and satisfaction, though there is a need for newness, as the effects can decrease in time (Layous, Nelson, & Lyubomirsky, 2013). To quote:

> *"To avoid adaptation, happiness seekers should vary their positive practices (which activities to perform, how many, how often, and with whom). Additionally, the more motivated individuals are to pursue happiness (Lyubomirsky et al., 2011), the more their families or cultures endorse this pursuit, and the more resources (e.g., time, effort) they have to accomplish it, the more likely they are to maintain their efforts,* (Lyubomirsky & Layous, 2013. p. 61).

With these insights in mind, the components provide parents with the practices of positive psychology with ideas for activities. In these components, parents may be encouraged to develop their ideas to fit their child and family, rather than provide a prescriptive programme of interventions.

Components For Strengths-Based Development and Well-being

Table 15. Brief Overview of Components Addressing Focus Group Themes & Literature Review

Component	Needs to be Addressed
Welcome	To provide parents with a welcoming and supportive environment. Group guidelines will explain that there is no judgement of parenting or a child's behaviour as this was raised as a potential barrier to participation by focus groups. (FG1 Line 275)
Research Aims & Overview of Workshops	The research aims to be explained to parents, permission would have previously been sought, and the study explained, however, a brief overview will help parents understand the evaluation.
Positive Introduction PPI	This activity is adapted from Well-Focus (Riches et al., 2015) a PPI that focuses on highlighting and focusing on themselves at their best. The literature review and focus groups revealed that parents face anxiety, stress and overload (FG2 Lines 312, 321, 344, 346, 348, 350). The aim is to help parents focus on themselves from a positive perspective and evoke positive emotions.
Introduction Task	Parents write five things that they are not able to do or areas of difficulty. These are passed to another person who introduces the parent based on their difficulties. This task is designed to highlight how we like to be seen by others as our best selves, and focusing on a deficit approach, as is often the case with autistic children, may be counter-productive. The 80/20 rule (Pareto's Principle) is offered for parents to apply to create a balance of attention: 80% of time and effort focused on strengths, talents, and interests. 20% of time and effort focused on developing children's developmental delays.
The Transition Curve (Fisher, 2012)	A discussion occurs regarding the uncertain future that some parents report and how the programme aims to ease parents' uncertainties. This component is expected to address issues of FG Theme parental concerns, sub-theme, and current concerns, a copy of the transition curve is found later in the chapter. Some focus group parents described experiences of 'bereavement' when their children were diagnosed. The transition curve identifies the process of the transition of change and associated feelings. The aim is to help parents realise that they are experiencing a process that is likely to come with different emotions at different stages. It is expected

Component	Needs to be Addressed
	that parents may identify with the curve and this may help them move along the transition. The discussion may help parents come to terms with change as well as a buffer against people who may try to limit parent's beliefs regarding future achievement.
Videos of Young Autistic Adults Describing Their Lives and Interests	The focus groups highlighted that parents do not know what to expect in the future, theme parental concerns, sub-theme, and current concerns. FG parents were keen to include young adults' examples to help them understand what life may be like in the future.
Autistic Development Theory and Model	Focus groups expressed a desire to understand autism and their child. The model seeks to explain how and why development may be disrupted and the onset of anxiety and related behavioural presentations. Presenting the theory may help parents understand how their child is currently developing and how they can support their child more effectively. Breaking the elements down is expected to help parents understand how small changes can support the child's development and decrease stress and anxiety for both parents and children. Parents have an opportunity to think about their child's presentation.
Sensory Perception and Over-done Strengths	This section is to help parents understand how enhanced sensory perception can lead to both strengths and challenges. The context will determine if the child is overloaded and stressed or not. When the child is not experiencing overload, enhanced sensory perception becomes a strength to build on. The aim should be to minimise the potentially intolerable sensory experiences so that enhanced perceptual functioning becomes one of the child's greatest strengths. This component aims to meet the needs raised in FG's theme child's presentation, sub-theme, and challenges.
Sensory-Overload Task.	This component aims to meet the needs raised in FG's theme child's presentation, sub-theme, and challenges. The aim is to help parents understand their child's potential difficulties undertaking simple tasks when their senses are overloaded. After the task discussion takes place on ways to reduce sensory input to help the child decrease overload.
Understanding Stress & Anxiety.	This section aims to teach parents how stress and anxiety can lead to adaptive behaviours and how caregiver responses can reinforce or negate such behavioural responses. Parents are encouraged to reflect on their child's behavioural responses. This component meets the

Component	Needs to be Addressed
	need to understand the cycle of family stress under the theme of parental concerns, sub-theme, and current concerns.
Methods to De-escalate Stress and Anxiety	FG themes parental concerns, current concerns requested coping strategies, and taking into account person-activity fit (Schueller, 2014), a variety of activities will be used. Visuals of these are provided later in the chapter. Anxiety Gremlin: a simple story with pictures about Gremlins that may help a child understand how worry thoughts can 'feed' the Gremlin, so he gets bigger and takes thoughts over, and changing thoughts can starve him. 'ABC': a model for parents to support the child to de-catastrophise and change explanatory style to a more optimistic style (~~M. E. P.~~ Seligman, 2007). 'Good Stuff Rubbish Stuff': this is an activity for the child to talk about negative experiences whilst undertaking a task. Two jars are used, a 'good' jar and a 'rubbish' jar. A child may take a marble, hold the marble whilst talking about the bad event/feeling and put it in the 'rubbish' jar. Parents respond to the child by helping the child think differently about the adversity which may help to decrease rumination. The parent then asks the child to share Three Good Things (Sexton & Adair, 2019) and put the three good marbles into the 'good stuff jar', while parents encourage positive emotion and celebration of the good things. Over time the child will have a visual reminder of the balance of more positive to negative. Feelings wheel: This wheel supports parents in teaching their children about feelings and helps them identify different feelings and create appropriate coping strategies. Controlled breathing: mindful controlled breathing to break the stress cycle.
Decreasing Uncertainty and Reminders	FG Theme parental concerns, and current concerns highlighted a need to decrease family stress, and decreasing uncertainty and setting expectations may help reduce family stress. Ideas and information are provided to parents to use with children to decrease uncertainty and reminders of steps to take with tasks (e.g. teeth brushing) using visual supports and reminders. Parents may generate ideas for age-appropriate support for older children.
Managing Daily Life Task	Focus groups were clear that they wanted to learn how to help their child but were frustrated with the system and lack of support. This task reinforces that parents can adapt interventions and support to

Component	Needs to be Addressed
	individualise for their child and development both now and in the future, building family self-reliance. This task helps parents plan how they will use their new understanding to support their child to manage in daily life.

Component	Needs to be Addressed
Understanding Experiential Learning and Concrete Thinking	Autistic children may have a literal understanding (Vicente & Falkum, 2023). Teaching is best when it is supported by visual information, life-relevant and motivating. Children may need the links made explicit between their aspirations and the skills they will need to fulfil them. If a young person wants to go to university, they need functional life skills and academic attainment. To motivate children, linking new skills with interests and ambitions may be helpful. Examples are provided of motivators for children of a younger age, for example, instant gratification (i.e. chocolate button for attempting a new word), and how motivators should use them alongside process praise.
Age-Related Functional Skills	This task asks parents to tick off skills that the child has mastered and highlight functional skill development needs. Functional skills may be delayed in autistic children and have been linked to parental intrusiveness, (or being overly involved in daily activities), and child anxiety (Drahota et al., 2011). It is envisaged that if a parent is intrusive, which has led to delays in developing functional skills, this task will highlight it to them. Attentional differences mean that children may not automatically learn from those around them. Parents may need to identify gaps in learning and what learning opportunities are needed to prepare the child for the future. This activity may meet the needs of FGs identified under the theme child's presentation and sub-theme challenges.
Goal Planning	Under the FG theme Feedback for the programme, sub-theme content, parents expressed a need to identify and set goals. A model to identify goals is provided with the seven steps to developing overarching goals and smaller, sub-goals to achieve them. Goal planning in this way may help parents to plan their child's development using a strengths-based approach. Group task. Using the goal of going to university, what skills does the individual need to be successful? This task is designed to help parents unpick the broad array of life skills that a young adult needs to leave home and live independently.

Component	Needs to be Addressed
'PERMA'	PERMA theory (Seligman, 2018) is explored with parents to help understand elements that people need to flourish in life. A discussion takes place on the different elements, and how parents can build each to create the opportunity to flourish. The literature review found that autistic children face poor outcomes and escalating mental health problems (e.g. Dillenburger, Jordan, McKerr, & Keenan, 2015). Encouraging parents to consider elements their children need for well-being may enable children and their parents to be more resilient and may buffer against poor outcomes and mental health problems. This component addresses the theme of the child's presentation, sub-theme, and challenges.
Video of Autistic Young Adults' Developmental Journey Using Strengths-based Development	The video aims to provide a positive, strengths-based example to reinforce parents' perceived value of special interests and strength-based development and increase hope. Parents are asked to identify myths about autism that the video has debunked. This meets the theme FG parents identified as needing positive role models under the theme feedback for the programme and sub-theme, content.
Strength Development	This element asks parents to spot their children's strengths that can be built on (skills, abilities, interests, talents, traits or characteristics) and how these can be expanded.
Positive Emotions & Broaden and Build Theory	Strategies to build positive emotions into the day are shared with parents that are adapted PPI: E.g. Gratitude activities; Humour; music and the 3-2-1 rule.
Engagement	Parents are taught about the concept of engagement, and using special interests is a unique gift to enable autistic children to become engaged. Special interests have been linked to flow experiences (E.g. Mottron, Dawson, & Soulières, 2009) and are a positive aspect of autism which can be drawn upon to enhance well-being and create a meaningful life.
Relationships	Autistic children can have difficulty understanding relationships and social rules due to their development disruptions. Strategies that may help children are offered, such as social stories for explaining social rules and activities that build the child's opportunity to engage with others.
Meaning	The concept of meaning, of being part of something greater than yourself, is discussed with parents. Parents are invited to share ideas

Component	Needs to be Addressed
	on how they can support the development of meaning for their children. Ideas such as doing things for others, joining environmental groups, and using strengths to create positive change are shared with parents.
Achievement	How parents are planning on using strengths (enhanced perceptual functioning and special interests) to build the opportunity to achieve. Discussion on creating meaningful goals and breaking them down into small achievable steps.
Individual Planning Task	Parents need to reflect on how they are going to plan for their child's development. How will the day look?

Discussion of Components

Understanding Autism Through ADT

Some parents in the focus groups reported that they were searching for more information about autism. ADT offers a potentially casual model of autistic development that may enable parents to understand their child from a developmental perspective, rather than the current perspective of disorder or deficit. The theme of Positive Perception was highlighted in the focus groups with parents reporting the challenges faced by professionals focusing on perceived deficits at odds with their desire to focus on the positive.

The theory will be visually presented, as in this thesis. Theoretically, parents understanding their child through the lens of ADT should help them identify their child's needs and how they, as parents, may accommodate them. Providing this component visually may also enable parents to understand the complex interplay of factors that may impact their child. In doing so, parents may begin to identify the adaptations they can make to maximise development and minimise the disruption of sensory overload, enhanced stress, and external barriers. The adaptations may not be extreme, for example, simply changing a ceiling light shade from a down-lighter to an up-lighter may protect the child from the over-whelm of the light bulb glare.

Stress Reduction Strategies

The Adapted Phenotype Theory (APT) previously discussed in this thesis, highlights the body of evidence showing that autistic individuals may have a heightened stress response. To protect from potentially harmful outcomes of toxic stress (Shonkoff et al., 2012), it has been proposed that children require a present and supportive parent.

Parents have also been shown to experience stress, (Estes et al., 2013) and this, along with fears for the future have been expressed by some parents in the focus groups under the theme of Parental Concerns.

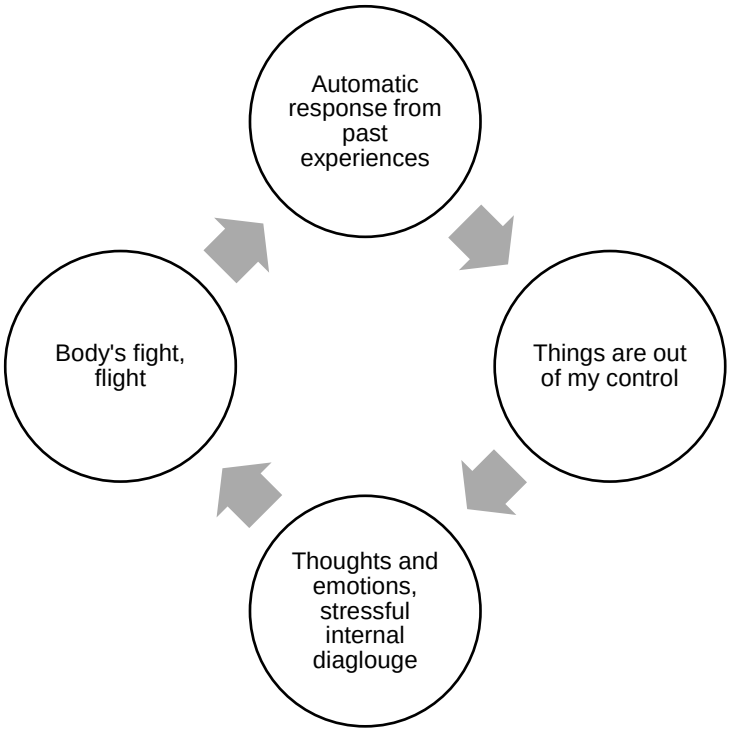
Decreasing stress for parents and autistic children and increasing well-being by utilising positive psychology activities is of utmost importance, therefore several stress reduction strategies have been identified for this component.

Parents are aware of cycles of stress and anxiety within their families and some focus group participants requested stress reduction strategies under the theme Parental Need. The following activities have been identified as potentially beneficial stress-reduction strategies:

A simple visual representation of the stress cycle will help parents see where it is possible to break the cycle and why strategies should work both for themselves and their children. The visual representation shows parents the interlinked cyclical nature of thoughts, feelings and
Physiology. Parents may be taught the stress cycle and controlled breathing techniques to interrupt this cycle and de-escalate stress, as this method to decrease stress and anxiety has been proposed as a more appropriate first response than prescribing medications (Jerath et al., 2015). Parents may also be encouraged to engage in this activity with their children daily, and when the child is distressed, to manage both parent and child stress.

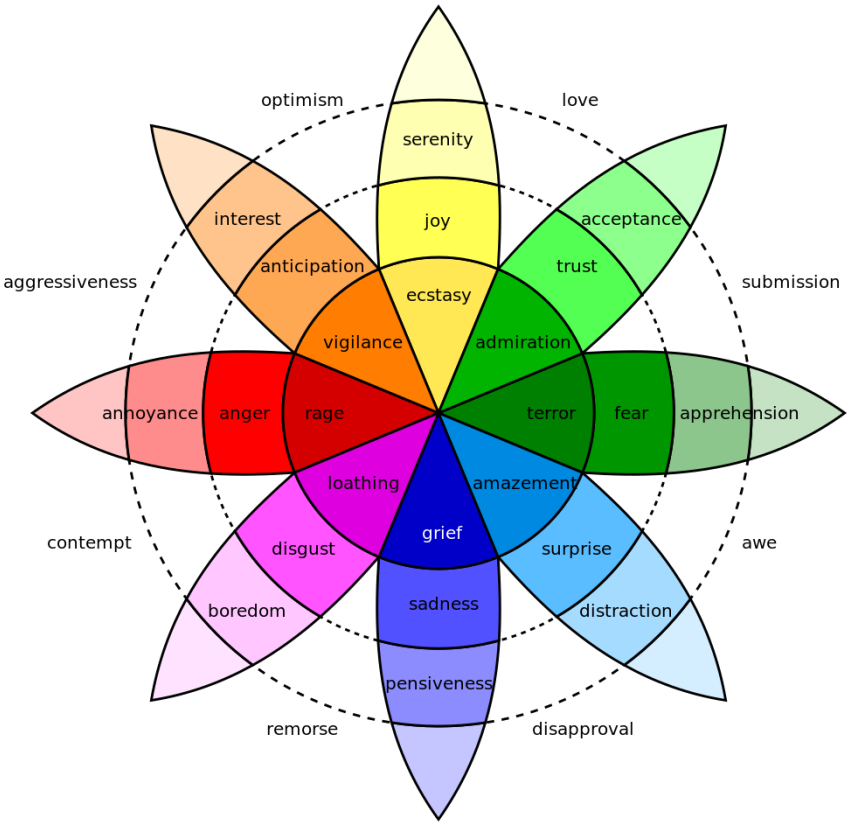
- Teach parents controlled breathing exercises to interfere with the stress cycle during distress. This will be practised with parents.

Figure 14. Simple Stress Response Visual



- Plutchik's emotion wheel (Plutchik, 2001) provides eight primary emotional dimensions of related emotions, that vary in intensity and are arranged as four pairs of opposites. It was considered important to include the emotion wheel as typically, autistic children are taught the core eight emotions (Ryan & Charragáin, 2010) and this is not reflective of the varied emotional landscapes that humans experience. Parents may use the wheel to discuss the emotions and the possible associated behaviours. In this component, parents are encouraged to expose their children to greater emotional literacy by modelling and talking about their own emotions as well as supporting their children to identify their own.

Figure 15. Pluchik's Emotion Wheel (2001)



- The 'Anxiety Gremlin' is a simple story with pictures about Gremlins. It conveys that worries or anxious thoughts can 'feed' the Gremlin, so he gets bigger and takes thoughts over, and changing thoughts can starve him.
  'Good Stuff Rubbish Stuff': This is a strategy to share experiences that have negatively impacted the child. The child uses a marble to represent the adversity, and the parent and child go through the 'ABC' process (Seligman, 2007), originally proposed by Beck (2015) when this is complete the child puts the marble in the rubbish jar. The parent then asks the child to share Three Good Things (Sexton & Adair, 2019) and put the three good marbles into the 'good stuff jar', while parents encourage positive emotions and celebration of the good things as well as constructive responses to challenges and difficulty. Over time, the child will have a visual reminder of the balance of more positive to negative experiences.

PERMA Theory

PERMA theory (Seligman, 2018) will be explored with parents to understand the elements that people need to flourish in life and how parents can build each element to create the opportunity to flourish.

Positive Emotions and the Broaden and Build Theory

Broaden and Build theory (Fredrickson, 2003) is explored concerning building positive emotions. Some ideas for building positive emotions are provided and parents may be encouraged to generate ideas to build positive emotions into the day. There are many positive emotions, and widely researched in the area of PP. are those of gratitude and humour. Ideas that are shared with parents are adapted to Positive Psychology Intervention through Gratitude activities (Cunha et al., 2019) and humour (Wellenzohn, Proyer, & Ruch, 2018).

Engagement

Parents are taught about the concept of engagement, and how special interests are a unique gift to enable autistic children to become engaged. Special interests have been linked to 'flow' experiences (Mottron, Dawson, & Soulières, 2009) and are a positive aspect of autism which can be drawn upon to enhance well-being and create a meaningful life.

Relationships

Autistic children may have difficulty understanding relationships and social rules due to their developmental disruptions. Strategies that may help children are offered, such as social stories (Scattone, Wilczynski, Edwards, & Rabian, 2002) for explaining social rules and activities that build the child's opportunity to engage with others. Parents are encouraged to identify relationships with supportive adults that give the child the opportunity to further develop the relationship and create meaning by engaging in acts of kindness, which may also feed into meaning and achievement. For example, a child may spend time with a parent baking a cake for a grandparent. This quality time may support the relationship with the parent. Taking to cake to the grandparent, as an act of kindness, may serve to nurture the child-grandparent relationship.

Meaning

The concept of meaning, of being part of something greater than yourself, is discussed with parents. Parents may share ideas of how they can support the development of meaning for their children. Ideas such as doing things for others, joining environmental groups and using strengths to create positive change are shared with parents.

Achievement

The final component is that of achievement. Autistic children often hold passionate personal interests over long periods, and these may bring unique opportunities to build achievements. The interests that autistic children have can bring the chance to enable children to achieve if they are allowed to immerse themselves and develop these interests. Therefore, autistic children's interests can be considered a strength on which to build and develop. This section is concerned with how parents are planning on using strengths unique to autism, such as enhanced sensory perception and interests, to build the opportunity to achieve and engage in strengths-based development. For example, if a child enjoys dinosaurs, but hand-eye coordination needs support, the child could be encouraged to colour in dinosaur pictures. This activity may give the child the motivation to undertake a difficult task (using a pencil) and promote development.

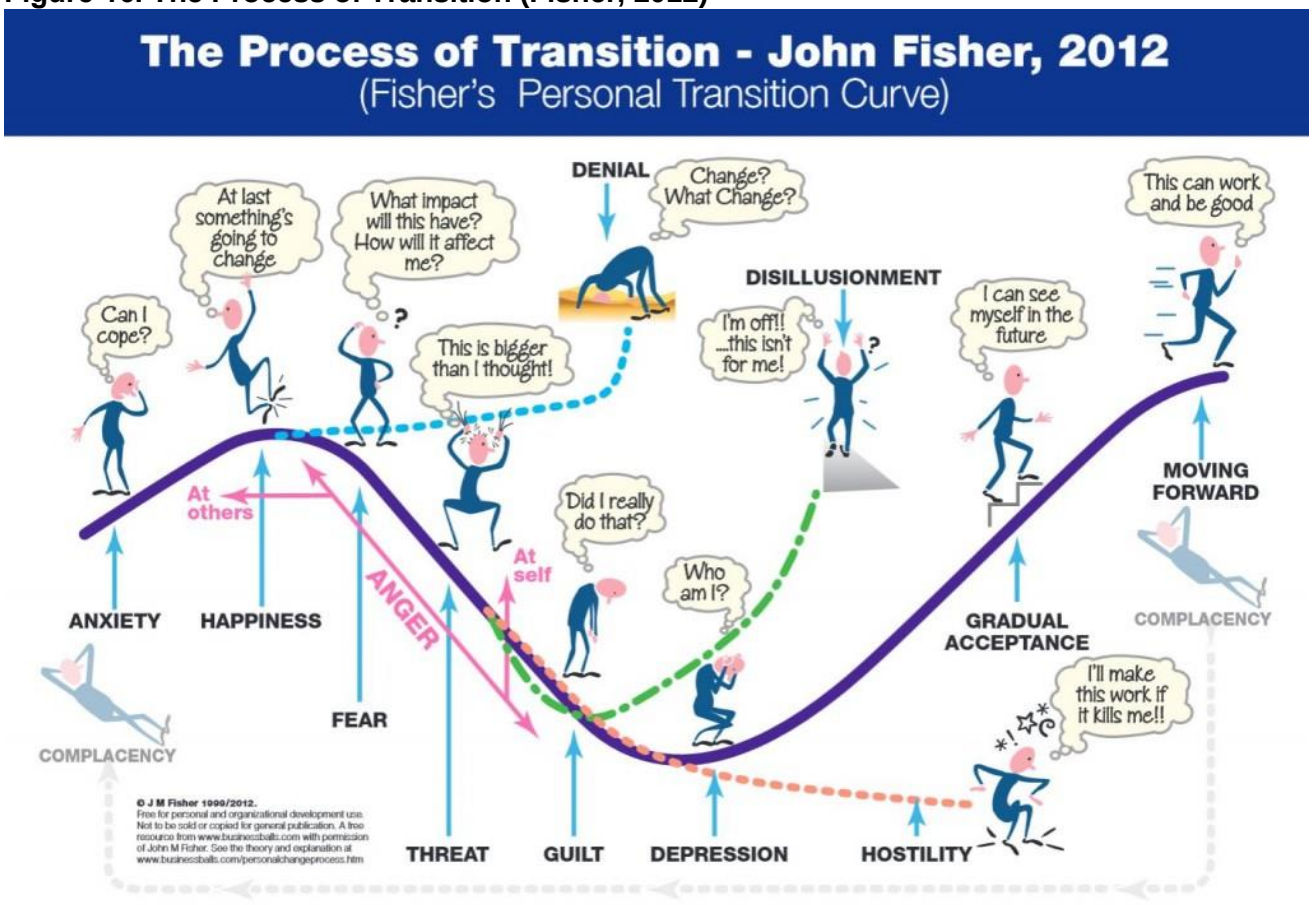
Strengths-Based Development

Some focus group participants reported a lack of balance with interventions received from the NHS and others, focusing on the child's area of difficulty rather than strengths. This component seeks to reframe perceptions of their children's interests, which are often perceived as restricted, repetitive behaviours. This component will consider interests as a 'superhero strength', to be embraced and nurtured. The reframing will aim to help parents understand that autistic interests can be a phenomenal strength when nurtured, providing the opportunity for flow experiences that build positive experiences, engagement, meaning and accomplishment. Reframing and encouraging interests may also help parent's perception of their child and their strengths and difficulties.

The Transition Curve

The theme of Parental Concerns included some parents feeling a sense of 'bereavement' post-diagnosis. It could be suggested that the parents use this term to identify their feelings because it is familiar and is one of process. The process that parents are reporting may be one of change rather than bereavement. The Transition Curve (Fisher, 2012) provides a visual overview of the Process of Transition, with the thoughts and feelings of each stage and the outcomes of possible denial, disillusionment and hostility if people do not continue the transition. The visual aid could work as a catalyst for discussion about the journey of change and how the process of change can come with thoughts and feelings that are typical and not unusual. Parents may be asked if they can identify themselves as having experienced the journey or if they are still experiencing it, and if so, what could help them move through the stages? The purpose of this component is to alter the perspectives of parents from one of possible loss to one of change.

Figure 16. The Process of Transition (Fisher, 2012)



Balancing Focus

Under the theme of Content, the focus group participants highlighted a need for a positive perception of their children and for their strengths to be developed. To highlight the need to balance the focus of intervention or activities, an introductory task, described below, has been developed.

After parents have introduced themselves, they are tasked with writing five things that they are not able to do or things they find difficult. These are then passed to another person to introduce them based on their difficulties. This task is designed to highlight how we like to be seen by others as our best selves. Focusing on deficits, as is often the case with autistic children, may be counter-productive for the child's well-being.

To help parents re-focus their balance of attention the 80/20 rule (Pareto's Principle) is offered:

- 80% of time and effort focused on strengths, talents, and interests.
- 20% of time and effort focused on developing children's developmental delays.

Insight Into Adult Life

Under the Parental Concerns theme, parents also highlighted an unknown future and a need to include positive adult stories in the Content theme. This may be achieved through the use of videos of young adults describing their lives. This may also help parents to raise their expectations for their child's future and decrease their anxieties about the future, should they have them.

Sensory Over-Load Discussion and Task

This task is designed to help parents experience sensory overload while attempting to complete a simple task. Discussion takes place on the impact sensory overload can have on a child's ability to perform and learn. Enhanced sensory perception is discussed in terms of being a strength in some environments where sensory stimuli are tolerable, and a weakness when stimuli are intolerable. In this task, parents are asked to colour in a picture whilst being over-exposed to sensory stimuli. Standing on one leg mimics vestibular difficulties; wearing washing-up gloves mimics proprioception difficulties; the researcher loudly talking and being disruptive mimics the auditory hyper-sensitivities that can be experienced. It is envisaged that parents experiencing these tasks may be more aware of environmental stimuli and how to adapt to the environment for their child.

Decreasing Uncertainty

To decrease uncertainty, parents are given examples of visual supports, that have been used successfully to decrease uncertainty and provide routines and expectations for autistic children (Ospina et al., 2008). The examples will provide visual support for step-by-step tasks, such as teeth brushing, daily visual schedules and adaptive technologies such as time timers.

Understanding Learning

It has been proposed that autistic children benefit from multi-sensory (visual and auditory) learning (De Silva & Dissanayaka, 2018). In this component, discussion takes place regarding motivation to learn, and how humans usually only learn what is relevant to them. Children may need the links made explicit between their aspirations and the skills they will need to fulfil them. For example, if a young person wants to go to university, they need functional life skills as well as academic attainment. To motivate children, linking new skills with interests and ambitions can be helpful. Examples are provided of motivators for children of a younger age, for example, instant gratification (i.e. chocolate button for attempting a new word), and how motivators should use them alongside process praise to provide internal motivation for the child and reward the attempt.

Parents may be encouraged to slowly adapt the reward system from instant gratification to longer-term reward systems, such as reward charts, with examples provided.

Age-Related Functional Skills

This component is a checklist of functional skills and approximate ages when these should be expected is provided for parents. Parents may be encouraged to check off what skills their child has attained to date and what they would like to prioritise helping their child gain. Functional skills may be delayed in autistic children and linked to parental intrusiveness (parents undertaking tasks that should be done by the child) and child anxiety (Drahota et al., 2011). It is envisaged that if a parent is intrusive, which has led to delays in developing functional skills, this task will gently highlight it to them.

Goal Setting and Planning

In the focus groups, some participants highlighted the importance of setting goals for their child to support their development under the Programme Content theme. This aims to help parents break down long-term goals into smaller achievable goals. This should help the children achieve success and provide additional motivation to work on the next steps. A coaching model is provided in this component to help parents undertake the planning. The steps are as follows:

Assess:	Where are we in the here and now?
What:	What do you/your child want to achieve or work towards?
Enabled:	What skills are needed? Have they learnt them yet?
Strengths:	What strengths are being drawn on?
Options:	What are the opportunities or options available? Am I being creative enough?
Motivation:	How motivated is the child to achieve this goal? How could you help your child be more motivated?
Experience:	Go put the plan into action!

Individual Planning Task

This component is a planning task that offers a visual tool to plan strategies in the areas of:

- Strength development and expansion.
- Developing Well-being Using PERMA (Seligman, 2018).
- Reducing anxiety and fear of failure.
- Developing Life and communication skills.

Next Steps

This chapter has outlined the key components that may be incorporated into a strengths-based intervention aimed at supporting the development and well-being of autistic children and their families. The design of these components aligns with the development phase of the UK Medical Research Council and the National Institute for Health Research's jointly commissioned guidance for developing and evaluating complex interventions (Skivington et al., 2021b). This phase involves either creating a new intervention or adapting an existing one to a new context, informed by research evidence and theoretical understanding of the problem. As demonstrated in this chapter, some components of the proposed intervention have been adapted from existing approaches, while others have been newly developed in response to the evidence and conceptual frameworks explored throughout this thesis.

According to the guidance, the next step involves conducting a feasibility study to assess the intervention's acceptability, practicality, and overall design before proceeding to further stages of evaluation. The following chapter explores how these components were integrated into a series of parent workshops, titled *Flourishing Futures* and how the intervention was evaluated using a range of outcome measures for both parents and children.

CHAPTER SEVEN

FLOURISHING FUTURES:

PARENT-MEDIATED STRENGTHS-BASED DEVELOPMENT FOR AUTISTIC CHILDREN

Introduction

The previous chapter explored a range of components, both developed and adapted, that have the potential to enhance the development and well-being of autistic children. The next

step in developing a complex intervention involves assessing its feasibility. A critical part of this stage is identifying key uncertainties within the project.

This chapter will outline:

- How the outcomes of focus groups directly influenced the design of the programme
- The practical challenges of recruiting for workshops in a context where research and researchers are often met with mistrust by parents of autistic children, and the resulting impact on data collection and analysis
- The design of the programme as delivered
- The distribution of participants across evaluation and control groups
- Experiences of programme delivery
- Statistical findings from parent questionnaires within both the evaluation and control groups
- An exploration of the conclusions that can be drawn from the statistical data
- A reflection on how the programme experiences and findings relate to the concept of a ‘complex intervention’

Key Uncertainties

Recruitment

Recruitment of parents/carers of autistic children may be difficult as there has been historical mistrust from some parents towards a research focus and researchers, and this may impact recruitment and engagement. To help gain the trust of potential participants local community groups were used to promote the project.

Delivery

Parents who attended the focus groups gave feedback under the theme of ‘Delivery’ were keen to have group workshops and identified the value of peer support. Under this theme, parents requested to be provided with the additional resources of online support for the project, a website and online live chat.

The components were put into workshops, with a corresponding handbook, slide show and website with a private forum.

Under this theme from the focus groups. parents also requested the involvement of schools and support workers. This was beyond the scope of the project and therefore not actioned.

Measures

A key uncertainty is what psychological measures should be used for both parents and children. As this is a new programme and there is uncertainty regarding the impact of the programme on parents and children, therefore a broad range of measures is necessary. However, too many may put parents off and lead to loss of data through disengagement.

Engagement and Adherence

As a parent-mediated intervention, the success of the programme relies heavily on parents implementing the strategies at home. However, consistent adherence cannot be assumed. Parents may face barriers to attendance due to work commitments, caregiving responsibilities, or the demands of supporting an autistic child. To enhance both engagement and adherence, the programme is designed to be delivered in as few workshops as is practical, while still ensuring the content remains meaningful and effective.

Financial

The years between 2010 and 2020 have been described as *"a lost decade"* (Glasby, Zhang, Bennett, & Hall, 2021, p. 428), with austerity measures contributing to an increasing gap between the demand for and funding of adult social care. The authors highlighted a significant rise in the number of young people entering adult social care with complex and costly lifelong needs.

In parallel, reports on children's social care have pointed to rising demand and escalating costs, compounded by reductions in central government funding to local authorities. Among the top three financial pressures on local authorities are the Special Educational Needs and High Needs Block. Given these fiscal challenges across both child and adult social care, the financial viability of any new intervention must be a top priority.

To support cost-effectiveness, the intervention should be designed for delivery by a single facilitator and include the minimum number of workshops necessary, helping to contain staffing and associated expenses.

These key uncertainties are likely to emerge and evolve throughout the process, requiring a flexible approach during this phase of development. The following section outlines the creation of workshops for parents, which aim to teach the strategies and components that have been adapted and developed to support a strengths-based approach to parenting.

Method

Traditional or 'classical' approaches to assessing research effectiveness are typically statistical in nature. Accordingly, the initial outcomes of the workshops will be presented using quantitative data drawn from a range of measures. The chapter will then go on to examine the workshops through the lens of a 'complex intervention'.

A quantitative pilot or feasibility study was conducted to evaluate the intervention, involving UK-based parents of autistic children aged between 3 and 15 years. The aim was to assess the effectiveness of a parent-mediated, strengths-based developmental programme. Two workshops were developed to equip parents with the knowledge and resources necessary to implement the strategies with their children at home.

Although three workshops were originally delivered, it was subsequently determined that two sessions would be sufficient to maintain effectiveness, thereby increasing feasibility and reducing burden. The workshops were facilitated by the researcher in four different geographical locations: Hinckley, Enfield, High Wycombe, and Uxbridge. The sessions in Hinckley and Enfield were held in local community venues with meeting facilities, while those in High Wycombe and Uxbridge took place on a university campus.

The intervention was evaluated using a range of parent- and child-focused measures. The following sections detail the design, delivery, and data analysis stages of the study.

Programme Content

The *Flourishing Futures* programme consists of two workshops, each based on the key components outlined in the previous chapter:

1. **Managing Today**
2. **Flourishing Futures**

The purpose of the *Flourishing Futures* workshops is not only to introduce practical strategies but also to help parents understand the underlying goals of these and the research that supports them. Rather than simply providing a toolkit, the programme is designed to build parents' understanding of *why* the strategies work, fostering deeper engagement and more meaningful application with their families.

Workshop One: Managing Today

The first workshop, *Managing Today*, is designed to equip parents with practical strategies, drawn from the programme's core components, to support themselves and their children in navigating their current challenges. These strategies are intended to be immediately relevant, providing tools to manage stress, understand emotional responses, and begin building resilience in daily life. The components for this workshop are detailed in Chapter 6, a brief summary is provided below:

Workshop Components Overview

- **Welcome and Introduction to the Research**
  An outline of the programme's purpose, structure, and the evidence base supporting its development.
- **Positive Introductions**
  Adapted from the WellFocus PPI framework (Riches, Schrank, Rashid, & Slade, 2015), this activity invites parents to introduce themselves in a strengths-based way, encouraging a focus on positive identity and evoking uplifting emotions.
- **Introductions Task**
  A brief interactive exercise to foster group connection and engagement.
- **The Transition Curve**
  A model for understanding emotional responses to change and transitions, particularly relevant to the experiences of families of autistic children.
- **Videos of Autistic Adults**
  Short video clips featuring autistic adults sharing their experiences, offering insight, relatability, and a strengths-focused perspective.
- **Autistic Development Theory**
  An introduction to Ruth Howard's Autistic Development Theory, providing a theoretical foundation for the intervention's strategies.
- **Sensory Overload Discussion and Activity**
  A practical session exploring sensory sensitivities, including reflective tasks to help parents understand and support their child's sensory experiences.
- **Understanding and Managing Anxiety and Stress**
  Core psychoeducation on the causes and effects of anxiety and stress, with emphasis on co-regulation strategies.
- **The Stress Cycle**
  A visual and conceptual tool to help parents identify how stress builds and is released, both in themselves and their children.
- **The Emotion Wheel**
  An emotional literacy resource designed to help families identify, name, and process a range of emotions.

- **Decreasing Uncertainty**
  A component focused on practical ways to reduce unpredictability and support children through routines, preparation, and visual supports.

Workshop Two: Strengths-Based Autistic Development

The second workshop focuses on equipping parents with the tools and understanding needed to support their child's development through a strengths-based lens. Drawing on principles from positive psychology, the session is designed to help families foster growth, resilience, and well-being in everyday life.

The components introduced in this workshop are grounded in both theory and the practical needs of families, as detailed in Chapter 6. A summary of these components is provided below:

Workshop Components Overview

- **Understanding Learning**
  An introduction to how autistic children may experience and process learning, with an emphasis on individualised, strength-oriented approaches.
- **Age-Related Functional Skills**
  A review of developmental expectations and functional skills relevant to age, helping parents set realistic and meaningful goals for their child's growth.
- **Goal Planning**
  Practical tools and guidance for setting personalised, achievable goals that align with each child's strengths and developmental needs.
- **Strength Development**
  A core element of the workshop, focusing on how to identify, nurture, and build upon each child's unique strengths and interests.
- **Positive Psychology Interventions**
  Evidence-based techniques drawn from the field of positive psychology, adapted for use by parents to support both their child's and their own emotional well-being.
- **PERMA Theory**
  An exploration of Seligman's PERMA model (Positive Emotions, Engagement, Relationships, Meaning, and Achievement), used as a framework for supporting flourishing in family life.

- **Positive Emotions and Broaden-and-Build Theory**
  Discussion of how positive emotions expand thinking and build lasting resources—emotional, cognitive, and social.

- **Engagement**
  Understanding how to cultivate deep involvement in meaningful activities, for both children and parents.

- **Relationships**
  Strategies to strengthen positive, supportive family and community relationships.

- **Meaning**
  Helping families identify sources of meaning and purpose in everyday experiences.

- **Achievement**
  Supporting families in setting and celebrating personal and developmental achievements.

- **Individual Planning Task**
  A practical exercise where parents apply workshop content to begin creating a tailored development plan based on their child's strengths and family goals.

Programme Resources

Supporting Materials and Resources

To enhance engagement and reinforce learning, a range of supporting materials were developed as part of the *Flourishing Futures* programme. These resources were designed to be accessible, user-friendly, and aligned with the programme's values of inclusion, collaboration, and strengths-based development.

Parent Workbooks

Parent workbooks were developed as a key resource to accompany the workshops. Designed to be user-friendly and approachable, the 34-page workbook offered succinct, informal explanations of key content alongside space for notetaking and task completion. The workbook included activities that supported parents in developing tailored plans for their children, which they could take home and use as an ongoing reference.

Importantly, the visual design of the workbook featured bespoke artwork created by an autistic artist, reinforcing the programme's commitment to valuing neurodivergent contributions and perspectives.

Facilitator Slide Deck

A PowerPoint slide show was developed to guide the delivery of workshop content. This ensured consistency across all workshop groups, supporting facilitators in maintaining fidelity to the programme design and covering all key components in a structured format.

Video Materials

To provide real-life context and inspiration, the programme included short videos featuring autistic young adults. These videos offered insight into adult life, with a particular focus on strengths-based development in practice. The aim was to reduce parental uncertainty about the future and foster a sense of hope.

All contributors featured in the videos were fully informed of the research aims and provided consent through a Contributor Consent Form.

Online Resources and Community Support

Following feedback from focus group participants, a private online platform was created to offer ongoing support. Hosted within a members-only section of the programme website, the platform included a secure forum where participants could connect with one another, share experiences, ask questions, and receive support. The researcher moderated the forum and

was available to respond to queries, helping to sustain momentum between workshops and promote a sense of community.

Programme Evaluation

Parent Psychological Measures

Hope theory suggests that hopeful thoughts are associated with the perception that an individual can find paths to achieving their desired goals and the motivation to use them. Research indicates that more hopeful people are happier (Pleeging, Burger, & van Exel, 2021). Therefore, increased parental hope is considered a key outcome of this research.

Subjective well-being has the emotional and cognitive aspects of positive and negative affect (Ed Diener et al., 2010). A further aim of the intervention is to enhance parents' (or primary caregivers') well-being and decrease stress. It was therefore considered pertinent to measure these using questionnaires specifically designed for each state. To provide a quantitative measure of stress, hope and well-being, the following were utilised:

The scale of Positive and Negative Experience (SPANE) (Ed Diener et al., 2010)

SPANE is a brief 12-item scale asking how often various states are experienced. In a South African university student sample, Cronbach's alpha coefficients were reported as 0.84 for SPANE-P, 0.79 for SPANE-N, and 0.85 for SPANE-B, indicating good internal consistency (Du Plessis & Guse, 2017). Factor analyses across multiple studies support a two-factor structure corresponding to positive and negative affect (Espejo, Checa, Perales-Puchalt, & Lisón, 2020). The SPANE is a reliable and valid instrument for assessing positive and negative emotional experiences.

The Adult Hope Scale (AHS) (Snyder et al., 1991)

This is a 12-item measure of the participant's level of hope. The AHS is a 12-item self-report questionnaire designed to assess dispositional hope, grounded in Snyder's cognitive model. This model conceptualises hope as comprising two components, agency thinking, which is reflects an individual's determination to achieve goals. The second, pathways thinking, is the ability to generate routes to achieve such goals (Snyder et al., 1991). Multiple studies have found that internal consistency, construct, convergent and discriminant validity and is a psychometrically sound instrument (Snyder et al., 1991).

The Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1983)

The PSS is a ten item self-report instrument designed to measure the degree to which individuals perceive their lives as stressful. It assesses the extent to which situations in one's life are appraised as unpredictable, uncontrollable, and overwhelming. Respondents indicate how often they have felt or thought a certain way during the past month, using a 5-point

Likert scale ranging from 0 (never) to 4 (very often). Higher scores indicate higher perceived stress (“Perceived Stress Scale (PSS-10),” n.d.). The PSS-10 has shown demonstrated good internal consistency across various populations with a review indicating internal reliability and validity (E. H. Lee, 2012).

The Flourishing Scale (FS) (Ed Diener et al., 2010)

The Flourishing Scale is an 8-item measure of self-perceived success in various areas of life such as relationships, self-esteem, purpose, and optimism. Each item is rated on a 7-point Likert scale ranging from 1 ("strongly disagree") to 7 ("strongly agree"), with higher scores indicating greater psychological well-being. The original validation study indicating good internal consistency (Diener et al., 2011). Subsequent studies have found similar reliability coefficients. For example, a study among South African university students reported a Cronbach's alpha of 0.82 (“Psychometric properties of the Flourishing Scale for South African first-year students | Mostert | African Journal of Psychological Assessment,” n.d.).

Child Psychological Measures:

The literature review and focus groups have highlighted that autistic children’s anxiety increases with age and may become life-limiting (Gordon-Lipkin et al., 2018; Gotham et al., 2015; van Steensel & Heeman, 2017; van Steensel et al., 2012). The programme provides strategies to help parents support their children who are experiencing anxiety. For this study, children’s anxiety levels are a key indicator of change and a positive outcome.

ADT enables participants to understand their child’s unique presentation and factors that may lead to various behaviours and presentations, using a visual model. This aims to help parents support the child by dealing with the potential underlying causes of developmental delays and self-imposed coping strategies.

If ADT provides participants with an effective means of understanding and supporting their child, this should lead to decreased behaviours associated with autism. These will be part of the data collection reported by participants pre- and post-programme.

The following scales will be used to measure the effectiveness of the intervention on anxiety and autistic presentation and will be completed by the parent:

SPENCE children’s anxiety scale parent report (SCAS) (Nauta et al., 2004)

The scale asks caregivers to report on 39 items associated with anxiety, with the options of never, sometimes, often and always as possible responses. The measure provides an overall score for anxiety and sub-scales. The domains of the sub-scales are: panic attack; separation anxiety; physical injury; social phobia; obsessive and generalised anxiety. It was considered pertinent to include a measure of children’s anxiety as this is reported to be high

in the autistic population (Lau, et al., 2020) and as a core aim of the intervention is to enhance well-being and decrease anxiety.

The SCAS has demonstrated high internal consistency across various studies. For instance, a study involving a Cypriot sample reported a Cronbach's alpha of 0.92 for the total scale. The SCAS has shown good test-retest reliability. In the Cypriot study mentioned earlier, the test-retest reliability over an 8-week interval was reported as r = 0.88, suggesting stability over time (Essau, Anastassiou-Hadjicharalambous, & Muñoz, 2011). Confirmatory factor analyses across multiple studies have supported the original six-factor structure of the SCAS. For example, a study in a Danish sample confirmed the six correlated factors model (Arendt, Hougaard, & Thastum, 2014). The SCAS has shown strong correlations with other established measures of anxiety. In the German study, significant correlations were found between the SCAS and the Youth Self-Report and the Columbia Impairment Scale, supporting its convergent validity (Essau, Muris, & Ederer, 2002).

The Spence Children's Anxiety Scale (SCAS) was developed and normed using non-autistic populations. While it has been widely validated and adapted cross-culturally, its application in autistic populations requires careful consideration. Considering this, the measure is used with a further parent reported measure the Autism Treatment Evaluation Checklist.

The Autism Treatment Evaluation Checklist (ATEC) (Mahapatra et al., 2018)

This measure was created for researchers and practitioners to assess the impact of treatments or interventions. The caregiver responds to questions in the domains of:

- Speech, language and communication
- Sociability
- Sensory and cognitive awareness
- Health and physical behaviour

Each domain consists of several behaviours or symptoms that caregivers respond to on graded scales, three grades for the domains of speech, language and communication, sociability, sensory and cognitive awareness and four for health and physical behaviour.

Studies have demonstrated the ATEC's high reliability, Cronbach's alpha coefficients for the subscales range from 0.82 to 0.94, indicating strong internal consistency and concurrent validity (Geier, Kern, & Geier, 2013). ADT emphasizes understanding autistic development as a distinct and valid trajectory rather than a deviation from typical development. In this context, the ATEC's focus on monitoring individual progress aligns with

ADT's principles by assessing multiple domains, the ATEC can help identify areas of growth and strengths in autistic individuals. The ATEC's ability to track changes over time can provide good insight into the effectiveness of the intervention

Primary Research Questions

This study aimed to evaluate the effectiveness of Flourishing Futures, and the primary research questions are as follows:

- Does participation in Flourishing Futures increase parental hope, indicated by increased hope scale scores?
- Does participation in Flourishing Futures increase parental flourishing, indicated by increased scores on the flourishing scale?
- Does participation in Flourishing Futures increase positive parental experience, indicated by increased scores on the SPANE scale?
- Does participation in Flourishing Futures decrease negative parental experience, indicated by decreased scores on the SPANE scale?
- Does participation in Flourishing Futures increase parental affective balance, indicated by scores on the SPANE scale?
- Does participation in Flourishing Futures decrease perceived parental stress, indicated by decreased scores on the perceived stress scale?
- Does participation in Flourishing Futures decrease children's anxiety, indicated by decreased scores on the child anxiety checklist?
- Does participation in Flourishing Futures decrease parent-reported children's autism symptoms, indicated by decreased scores on the ATEC?

Table 16. Data from the following psychological questionnaires are being used to indicate change achieved in these primary research questions:

Primary Research Questions	Psychometric Questionnaire Used as Measure
Does participation in Flourishing Futures increase parental hope?	The Adult Hope Scale (Snyder et al., 1991)
Does participation in Flourishing Futures increase parental flourishing?	The Flourishing Scale (Ed Diener et al., 2010):
Does participation in Flourishing Futures increase positive parental experience?	The scale of Positive and Negative Experience (SPANE) (Ed Diener et al., 2010)
Does participation in Flourishing Futures decrease negative parental experience?	The scale of Positive and Negative Experience (SPANE) (Ed Diener et al., 2010)
Does participation in Flourishing Futures increase parental affective balance?	The scale of Positive and Negative Experience (SPANE) (Ed Diener et al., 2010)
Does participation in Flourishing Futures decrease perceived parental stress?	The Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)
Does participation in Flourishing Futures decrease children's anxiety?	SPENCE children's anxiety scale parent report (Nauta et al., 2004)
Does participation in Flourishing Futures decrease parent-reported children's autism symptoms?	The Autism Treatment Evaluation Checklist (ATEC) (Mahapatra et al., 2018)

Stage Two: Ethical Approval

Key ethical issues with the study would be obtaining informed consent, confidentiality, and the right to withdraw at any time. These are addressed in the participant information sheet provided to interested potential participants.

Ethical approval was sought from the Buckinghamshire New University Research Ethics Committee and a copy of these documents can be found in the Appendix O. The following documents were provided to the Committee:

- Ethics application form
- Participant Information Sheet
- Consent Form
- Letters seeking/granting permission for access to data/participants
- Materials for the recruitment of participants
- Evaluation Questionnaire
- Parent Workbooks
- Risk assessment

Ethical approval was granted, and the approval code was UEP2018Nov02.

Stage 3: Participant Recruitment

Recruitment Process

Participants were recruited via local groups, the Leicestershire Autistic Society, parent groups and practitioners. The email requested that they forward the Recruitment Flyer to parents. The recruitment flyer briefly described the project and asked interested parents to contact the researcher for further information via email.

When contacted by email, potential participants were sent the Participant Information and Participant Consent Forms to read and return.

Participants were assigned to one of six groups:

1. Evaluation Group A (Leicestershire Wednesday Workshops).
2. Evaluation Group B (High Wycombe Friday Workshops)
3. Evaluation Group C (High Wycombe Saturday Workshops)
4. Waitlist Control Group A (Enfield Saturday Workshops)
5. Waitlist Control Group B (Uxbridge Friday Workshops)
6. Waitlist Control Group C (Uxbridge Saturday Workshops)

Recruitment Difficulties

The original intention was to recruit one evaluation group and one waiting list control group. However, participant recruitment proved challenging, and final numbers were lower than anticipated. Although a significant number of parents expressed initial interest and often followed up with questions after being contacted, few progressed to full participation—culminating in the completion of all required measures.

On reflection, one likely barrier was the volume of paperwork required for data collection, which may have discouraged engagement. In response to these challenges, additional groups were organised on university campuses, and the original child age limit of 11 years was lifted to increase accessibility and broaden eligibility. These adaptations reflect the flexible and iterative approach recommended in the development of complex interventions (Skivington et al., 2021).

Stage Four: Delivery

Participants

Participants were parents of autistic children aged 3 to 15 years, with a mean age for the evaluation group of 8.83 years and a control group of 8.26 years. The total number of participants who completed the workshops and measures was 24 for the evaluation group and 19 for the control.

The mean number of the children’s comorbid conditions was 1.46 for the evaluation group, and it was 0.84 for the control group, with the mean of medications 0.96 for the

evaluation and 0.89 for the control group. The collection of this data was to check group similarities or differences in the event of anomalies in the data.

Data Collection

The evaluation groups completed the measures at the following time points:

- Time A: Immediately before participating in the workshops.
- Time B: Immediately after participating in the workshops.
- Time C: 3 months after participating in the workshops.

Waiting list control groups completed the measures at the following time points:

- Time A: 3 months before participating in the workshops.
- Time B: Immediately before participating in the workshops.
- Time C: Immediately after participating in the workshops.

Eight waiting list control group members agreed to complete further measures three months after participating in the workshops (Time D). Their data, therefore, contributed to both evaluation and control groups.

Procedure

The first evaluation group attended three workshops over three consecutive weeks in a community centre. During the initial workshops, it became apparent that too much time had been allocated for tasks and discussions; therefore, all subsequent workshops were held over two days, over two weeks. The workshops provided participants with the workbooks and a PowerPoint presentation was used to ensure that there was consistent information provided to all groups.

Participants were given the research support website address (as recommended by focus group participants), and this information was also provided in the participant workbook.

Some parents could not attend both workshops for various reasons, such as appointments, child sickness, and work commitments. The data from these participants was removed from the analysis

To further inform the study, researcher notes were taken after the workshops. These reflections are summarised in the Results section.

Outcome

Turning first to a statistical evaluation of the research from questionnaire data received and analysed.

Data Processing

The data was processed using SPSS and despite extensive work, there was a lot of data missing and several participants had to be removed from the study at the processing stage. Participants who completed Time A and C for the evaluation group, Time A and B for the waiting list control and B and D for the participants who were initially in the waiting list control, were included in the analysis. For the complete evaluation, there were 24 participants and 19 waiting list control participants whose data was included in the analysis.

Data analysis was conducted using SPSS. Some data from the remaining participants was also missing, so non-parametric tests were used to analyse the data.

It was initially planned that the measures would be taken at the end of the workshops, however, parents were strictly time constrained and during the initial workshops, 3 parents could not complete them. Taking a flexible approach, the data was collected pre-workshops and 3 months post-workshops.

To evaluate the impact of participation on parents and their autistic children, the data was analysed against the research questions. The Related Samples Wilcoxon Signed Rank Test was used with a significance level of $p = 0.05$. A summary of the findings for parent measures is presented in Table 17.

Evaluation

The new framework for developing complex interventions shifts the focus from simply determining whether an intervention “works” through hypothesis testing, to exploring broader questions about its impact, interaction with context, and potential contribution to system-level change (Skivington et al., 2021). Rather than seeking a binary outcome based solely on statistical significance, this approach encourages the identification of meaningful patterns, changes, and trends over time. In alignment with this framework, the results section presents mean group scores across the evaluation period, with a focus on examining directional changes and emerging trends, rather than solely confirming cause-and-effect relationships.

Results

Statistical results are presented initially in tabular form to give the reader an overview, and then graphically with a commentary after this section.

Table 17. Results of Each Measure

Table	Group	Evaluation Group		WL Control Group		Significance
		From	To	From	To	
16	Parental Agency	24.08	25.42	25.5	26	
17	Parental Pathway	24.05	26.5	28.13	26	
18	Hope	48.58	51.92	53.63	52	
19	Parental Flourishing	44.79	51.92	46.56	47.67	
20	Parental Positive Experience	21.14	20.95	20.13	21.17	
21	**Parental Negative Experience**	**18.5**	**12.29**	**16.94**	**16.44**	**Yes**
22	**Parental Affective Balance**	**2.64**	**8.67**	**3.9**	**4.72**	**Yes**
23	Perceived parental stress	19.46	19.48	19.47	20.71	
24	**Child Autism Treatment Evaluation Checklist**	**62.75**	**55.82**	**56.29**	**54.21**	**Yes**
25	SPENCE Child anxiety checklist	39.58	35.04	35.68	38.05	
26	Child panic attack – mean scores	6	5.17	5.28	5.68	
27	Child separation anxiety	8.17	7.67	7.57	7.68	
28	Child physical. Injury mean scores	5.58	5	5.59	5.11	
29	**Child social phobia mean scores**	**8.17**	**6.63**	**9**	**8.21**	**Yes**
30	Child obsessive mean scores	5	4.96	5.35	4.95	
31	Child generalised anxiety mean scores	6.67	5.63	6.71	6.42	

Results: Parental Agency, Pathway and Hope
Research Question: Does Participation in Flourishing Futures Increase Parental Hope?

A Wilcoxon signed-rank test was conducted to compare agency scores before and after the intervention in the evaluation group, and between the beginning and end of the three-month waiting period in the control group.

For the evaluation group, agency scores increased from a mean of 24.08 (SD = 6.74) at Time A to a mean of 25.42 at Time B (SD = 6.44).

In the control group, scores increased from a mean of 25.5 (SD = 3.34) at Time A to a mean of 26.0 at Time B (SD = 3.64).

The results were not statistically significant, p = .93 for the evaluation group and p = .84 for the waiting list control group (see Figure 18).

Figure 17. Mean Scores: Agency

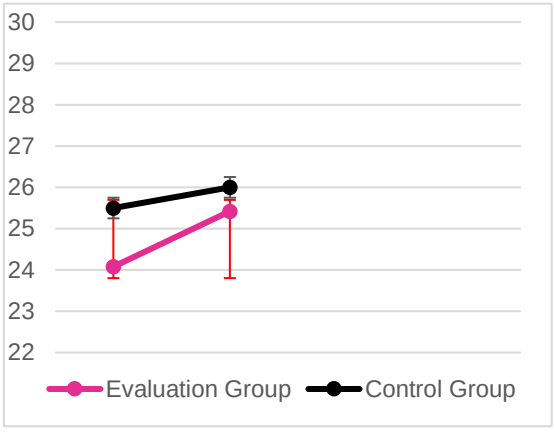
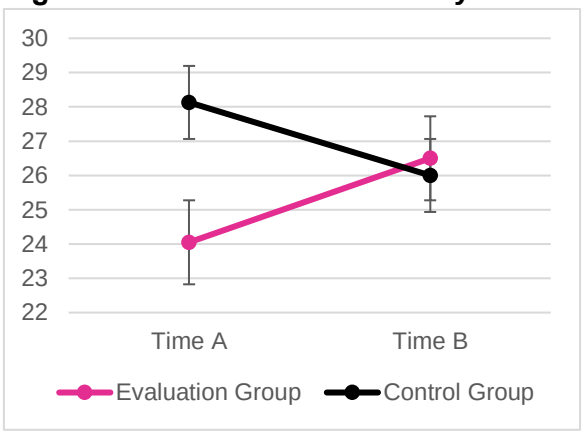


Figure 18. Mean Scores: Pathway



A Wilcoxon signed-rank test was conducted to compare pathway scores before and after the intervention in the evaluation group, and between the beginning and end of the three-month waiting period in the control group.

The evaluation group scores increased from a mean of 14.59 (SD = 36.66) at Time A to a mean of 15.05 at Time B (SD = 15.05). The results were not statistically significant, p = .93.

The control group scores decreased from a mean of 25.5 (SD = 36.52) at Time A to a mean of 26.0 at Time B (SD = 14.07), the results were not statistically significant, p = .84 (Figure 19).

The significance found in the control group is a downward trend of decreasing Pathway scores over time. This suggests that without appropriate intervention, parents may decrease Pathway thinking. Despite the evaluation groups Pathway thinking not showing statistical

significance, Pathway scores did rise over time, suggesting that participating in Flourishing Futures may help increase parents' Pathway thinking, though not to a statistically significant degree.

Flourishing Futures includes goal setting and planning with a variety of tools and a coaching model to apply. These components may have supported parents with their pathway thinking leading to this positive trend.

Figure 19. Mean Scores Hope

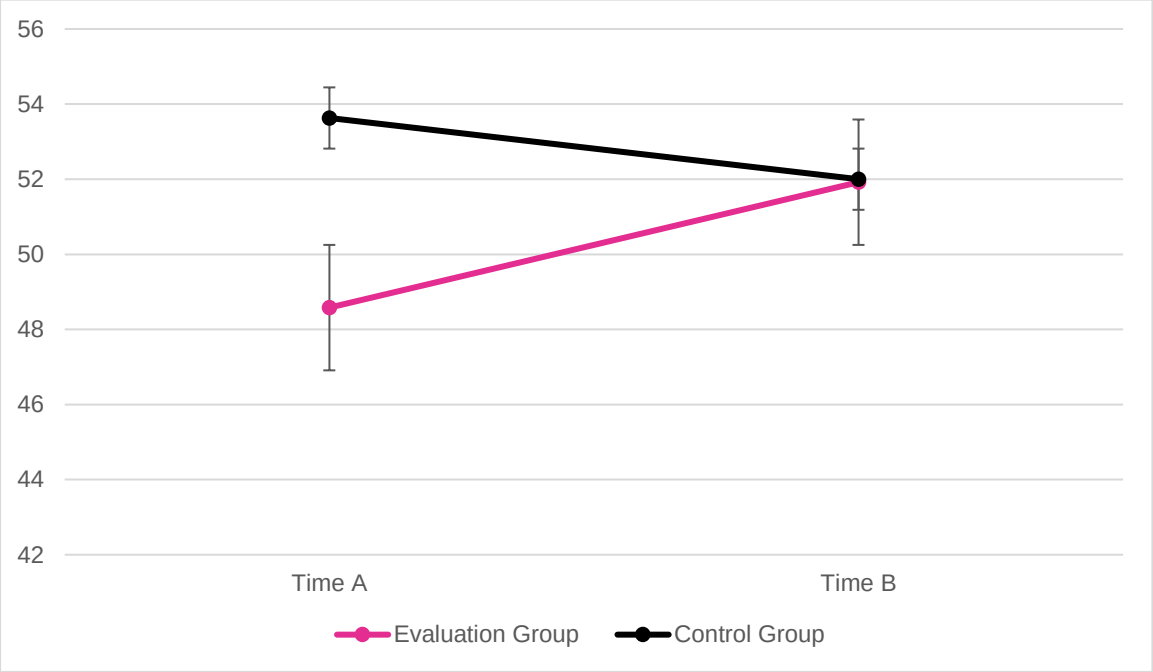


Figure 20. shows results for the Hope scale over the evaluation period. A Wilcoxon signed-rank test was conducted to compare pathway scores before and after the intervention in the evaluation group, and between the beginning and end of the three-month waiting period in the control group.

The Adult Hope Scale (Snyder et al., 1991) reports on Agency and Pathway and combined the scores provide an overall hope score. Figure 20. shows that the evaluation period saw an increase in the mean hope score for the evaluation group by 3.5 points and a decrease in WLC of 1.5. A Wilcoxon signed-rank test was conducted to compare overall hope scores before and after the intervention in the evaluation group, and between the beginning and end of the three-month waiting period in the control group.

For the evaluation group, scores increased from a mean of 50.6 (SD = 8.75) at Time A to a mean of 51.9 at Time B (SD = 51.9).

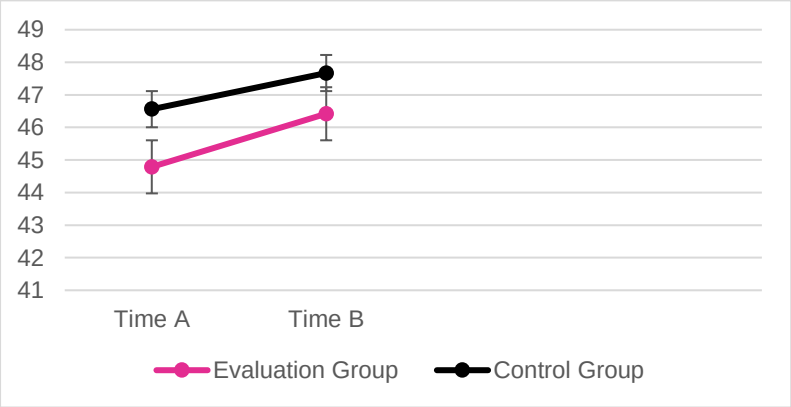
In the control group, scores decreased from a mean of 53.6 (SD = 5.94) at Time A to a mean of 52 at Time B (SD = 7.29).

The overall Hope p values were *p* = 0.21 for the evaluation group and 0.22 for the control group, so no statistical significance was found for this trend.

Results: Parental Flourishing

Research Question: Does Participation in Flourishing Futures Increase Parental Flourishing?

Figure 20. Mean Scores Parental Flourishing



A Wilcoxon signed-rank test was conducted to compare parental flourishing scores before and after the intervention in the evaluation group, and between the beginning and end of the three-month waiting period in the control group.

In the evaluation control group, scores increased from a mean of 44.7 (SD = 7.73) at Time A to a mean of 46.4 at Time B (SD = 7.2).

For the control group, scores increased from a mean of 46.5 (SD = 5.9) at Time A to a mean of 47.6 at Time B (SD = 4.71).

The results were not statistically significant, *p* = 0.10 for the evaluation group and *p* = 0.24 for the waiting list control group (see Figure 21).

Figure 21. shows that parental flourishing increased in both groups over time, though neither to a statistically significant level. Although both show an upward trend of flourishing, there is a greater difference for the evaluation group than controls, highlighting that participation may enhance flourishing though not to a level of statistical significance.

Results: Parental Positive and Negative Experiences

Does Flourishing Futures increase positive parental experience?

Does Flourishing Futures decrease negative parental experience?

The SPANE provides three scores, positive experience (Figure 20), negative experience (Figure 21) and affect balance in which scores can range from -24, the unhappiest, to 24, the highest affect balance and reportedly, the happiest.

Figure 21. Mean Scores Parental Positive Experiences

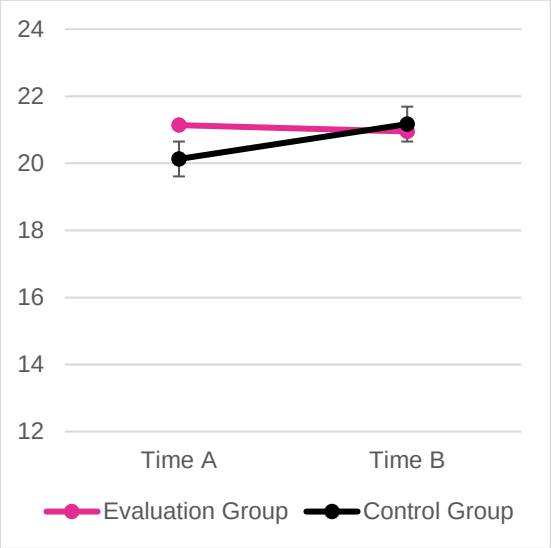
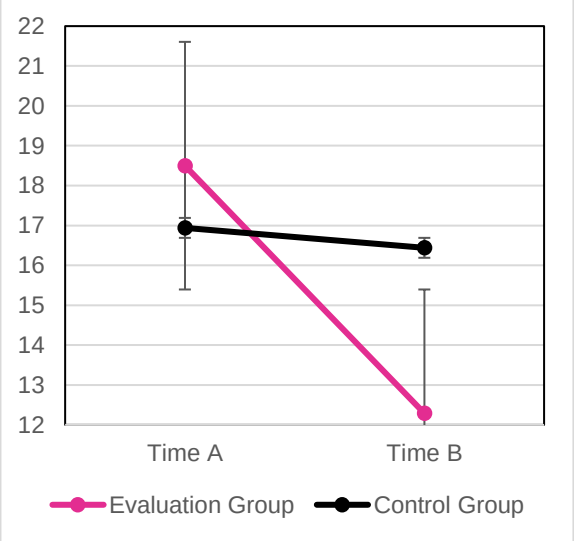


Figure 22. Mean Scores Parental Negative Experiences



In the evaluation control group, scores for the scale of positive experiences decreased from a mean of 21 (SD = 4.47) at Time A to a mean of 20.9 at Time B (SD = 4.11).

For the control group, scores increased from a mean of 20.1 (SD = 4.16) at Time A to a mean of 21.1 at Time B (SD = 4.48).

The results were not statistically significant, p = 0.0.81 for the evaluation group and p = 0.31 for the waiting list control group (see Figure 22).

Figure 22. shows there was a slight decrease in mean positive experiences for the evaluation group of 0.2, while the WLC rose by 1 during the evaluation period. These outcomes show that participation in Flourishing Futures does not lead to an upward trend of greater positive experiences at the time of test-taking.

In the evaluation control group, negative experience scores decreased from a mean of 18.5 (SD = 5.17) at Time A to a mean of 12.2 at Time B (SD = 9.47).

For the control group, scores increased from a mean of 16.9 (SD = 5.17) at Time A to a mean of 16.4 at Time B (SD = 5.80).

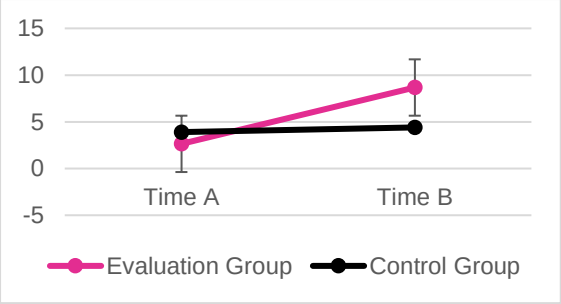
The results were statistically significant for the evaluation group, $p = 0.04$ ($\alpha = 0.05$) and not significant for the waiting list control group $p = 0.31$ (see Figure 23).

In contrast to this, Figure 23. shows that during the evaluation period, the mean scores for the WLC remained the same, there was a downward trend shown in the evaluation group for negative experiences. Parents in the evaluation group showed decreases in negative experiences to a significant level of $p = 0.04$ and p = 0.94 for the controls, therefore the null hypothesis can be rejected. This suggests that participation in flourishing futures may decrease parental negative experiences or parents' perceptions of negative experiences.

Results: Parental Affective Balance

Research question: Does Flourishing Futures increase parental affective balance?

Figure 23. Mean Scores Parental Affective Balance



In the evaluation control group, parental affective balance scores increased from a mean of 18.5 (SD = 5.17) at Time A to a mean of 12.2 at Time B (SD = 9.47).

For the control group, scores increased from a mean of 16.9 (SD = 5.17) at Time A to a mean of 16.4 at Time B (SD = 5.80).

The results were statistically significant for the evaluation group, $p = 0.04$ and not significant for the waiting list control group $p = 0.31$ (see Figure 24).

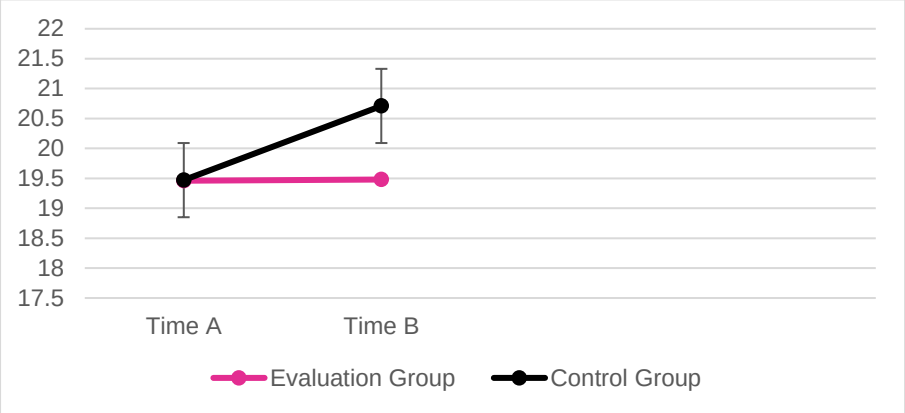
Figure 24. shows parental affective balance scores for Time A and Time B. The WLC group showed little change across time with $p = 0.60$, while the evaluation group scores changed to a level of significance with $p = 0.05$. This finding suggests that participation in Flourishing

Futures may positively impact parental affect balance over the time between test assessments.

Results: Perceived Parental Stress

Research question: Does participation in Flourishing Futures decrease perceived parental stress?

Figure 24. Mean Scores: Perceived Parental Stress



In the evaluation control group, perceived parental stress balance scores remained the same with a mean of 19.4 (SD = 5.16) at Time A to a mean of 19.4 at Time B (SD = 6.20).

For the control group, scores increased from a mean of 19.4 (SD = 6.85) at Time A to a mean of 20.7 at Time B (SD = 5.62).

The results were not statistically significant for the evaluation group, $p = 0.59$ and not significant for the waiting list control group $p = 0.16$ (see Figure 25).

Figure 25. shows that over the three-month evaluation period, Perceived Parental Stress showed a very small increase for the evaluation group $p = 0.59$ and an increase of over 1 score for the WLC group $p = 0.16$. This finding may highlight that Perceived Parental Stress is not impacted by participating in Flourishing Futures. Alternatively, the score may be indicative of energy being invested by parents into learning and change with a relaxation that might follow after the mastery of new skills and information.

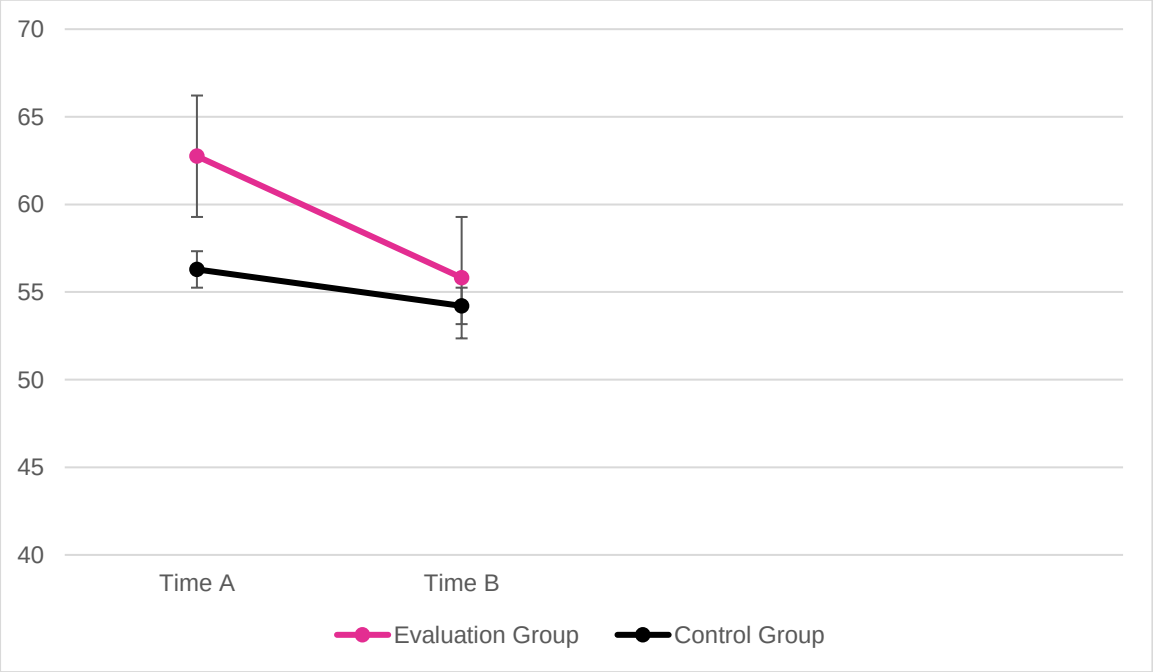
Child Outcomes

- **Does Parental Participation in Flourishing futures decrease children's anxiety?**
- **Does Parental Participation in Flourishing Futures decrease children's autism**

Results: Children's Autism Treatment Evaluation Checklist (ATEC)

The ATEC was created for researchers and practitioners to assess the impact of treatments or interventions. The caregiver responds to questions in Speech, language and communication; Sociability; Sensory and cognitive awareness; Health and physical behaviour. The overall score is the combined scores of the four domains. The following charts show the mean total scores for Time A and B for the evaluation and control groups.

Figure 25. Child Autism Treatment Evaluation Checklist Mean Scores



In the evaluation control group, Child Autism Treatment Evaluation Checklist Mean Scores increased from a mean of 62 (SD = 22.82) at Time A to a mean of 56 at Time B (SD = 24.84).

For the control group, scores increased from a mean of 56.2 (SD = 32.54) at Time A to a mean of 54.2 at Time B (SD = 28.67).

The results were not statistically significant for the evaluation group, $p = 0.59$ and not significant for the waiting list control group $p = 0.79$ (see Figure 26).

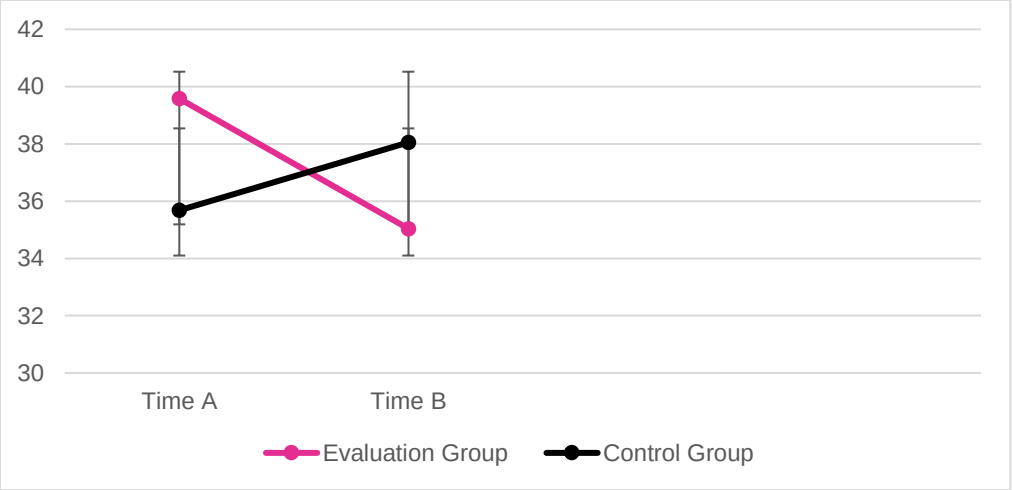
As Figure 26. shows the waitlist control group's total scores showed little change with a p value of $p = 0.02$, whilst the evaluation group showed a significant change in autism

symptoms with p = *p* = 0.02. The findings indicate that parental participation in Flourishing Futures may lead to decreases in overall displayed autism symptoms over three months. This is a positive early finding of improvements in children's autism symptomology. The waitlist control group symptoms also decreased to a non-significant level; however, the control group's decrease may be supportive of the developmental aspects of Autistic Development Theory, with changing presentation of symptoms over childhood.

However, whilst these are positive outcomes, it should be noted that the ATEC questionnaire is completed by parents, and parents have been found to have decreased negative effects during the evaluation period. This trend may be showing because parental perception of their child's autistic symptomology has shifted, and this has led to the statistically significant findings.

SPENCE Child Anxiety Checklist Parent Report
Research Question: Does Flourishing futures decrease children's anxiety?

Figure 26. SPENCE Child Anxiety Checklist Parent Report



In the evaluation group, SPENCE Child Anxiety Checklist Parent Report mean scores increased from a mean of 39.5 (SD = 19.24) at Time A to a mean of 19.03 at Time B (SD = 35.04).

For the control group, scores increased from a mean of 35.6 (SD = 24.79) at Time A to a mean of 38.05 at Time B (SD = 19.36).

The results were not statistically significant for the evaluation group, *p* = 0.17 and not significant for the waiting list control group *p* = 0.50 (see Figure 27).

Figure 27. shows the WLC group's mean anxiety scores increased over time while the evaluation group's anxiety scores decreased, though statistical significance was not shown in either group. The p values were $p = 0.17$ for the evaluation group, and $p = 0.50$ for the WLC group. The trends are of interest as the groups are opposing. As ADT would predict, without an intervention and strategies to support the child in the waitlist control group through their anxiety, it is likely to increase over time. The programme aimed to help parents in the evaluation group use perspectives and resources to support their child through their anxiety and the trend shown is indicative that this may have happened.

An alternative explanation for the decrease in anxiety mean scores in the evaluation group could be that the shift in parents' negative affect in the evaluation group has impacted the child's anxiety, as they may be intertwined.

Child Anxiety Sub Scales

The following figures report mean scores for both groups at times A and B.

Figure 27. Child Panic Attack Means

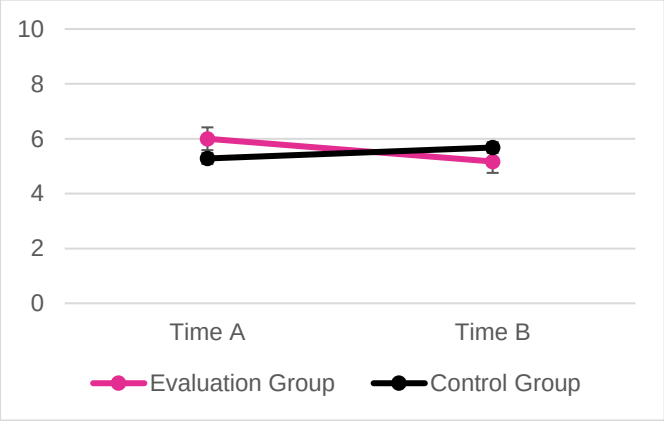
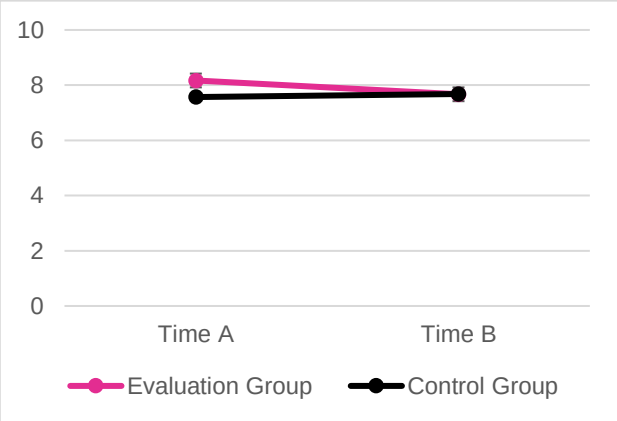


Figure 28. Child Separation Anxiety



The sub-scale scores found no statistical significance in the Panic Attack sub-scores, with evaluation group p value of $p = 0.31$ and control group $p = 0.53$. In the evaluation group, scores increased from a mean of 39.5 (SD = 19.24) at Time A to a mean of 19.03 at Time B (SD = 35.04) (Figure 28).

For the control group, scores increased from a mean of 35.6 (SD = 24.79) at Time A to a mean of 38.05 at Time B (SD = 19.36).

Separation Anxiety were not statistically significant with an evaluation group p value of $p = 0.29$ and WLC group $p = 0.81$ (Figure 29). In the evaluation group, scores increased from a mean of 8.16 (SD = 4.39) at Time A to a mean of 7.66 at Time B (SD = 8.18).

For the control group, scores increased from a mean of 7.58 (SD = 10.59) at Time A to a mean of 7.52 at Time B (SD = 4.44).

Figures 28. and 29. show a downward trend in Panic Attack and Child Separation Anxiety in the evaluation group and a very slight upward trend in the control group. This suggests that parental participation in Flourishing Futures may impact the child's Panic Attack and Separation Anxiety positively with a reduction in scores over time.

Figure 29. Child Physical Injury Means

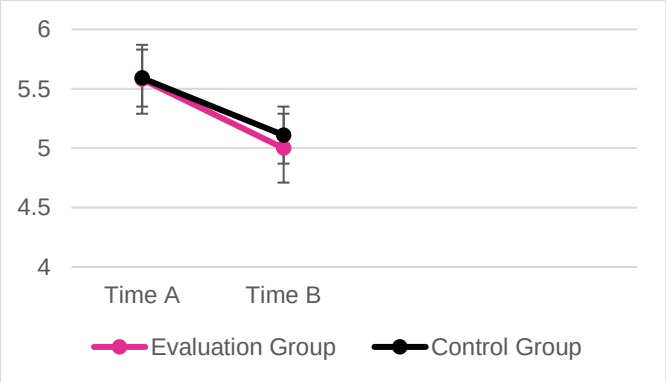
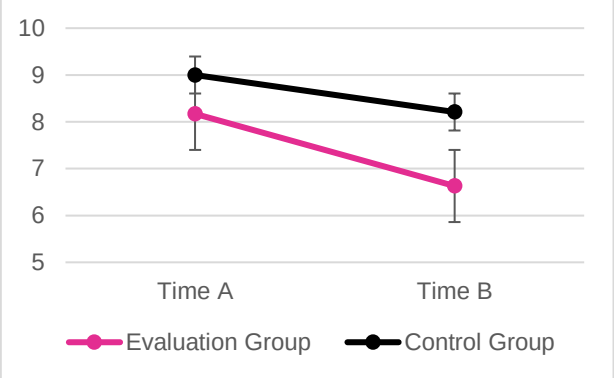


Figure 30. Child Social Phobia Means



Child Physical Injury Anxiety and Social Phobia are showing a downward trend for both evaluation and WLC groups. Statistical significance was not found for Child Physical Injury with p values of $p = 0.10$ for the evaluation group and $p = 0.86$ for the WLC group (Figure 30).

In the evaluation group, scores decreased from a mean of 5.58 (SD = 2.93) at Time A to a mean of 5 at Time B (SD = 3.07).

For the control group, scores increased from a mean of 5.58 (SD = 9.08) at Time A to a mean of 5.10 at Time B (SD = 3.31).

Significance was found in the evaluation group for Social Phobia with a p value of $p = 0.04$ and a control group $p = 0.32$ (Figure 31).

In the evaluation group, scores decreased from a mean of 8.16 (SD = 10.78) at Time A to a mean of 6.62 at Time B (SD = 9.17).

For the control group, scores increased from a mean of 9.05 (SD = 8.27) at Time A to a mean of 8.07 at Time B (SD = 5.56).

Outcomes for Child Social Phobia indicate that parental participation in Flourishing Futures influences children's social phobia to a level of statistical significance and this is a welcome trend.

Figure 31. Child Obsessive Means

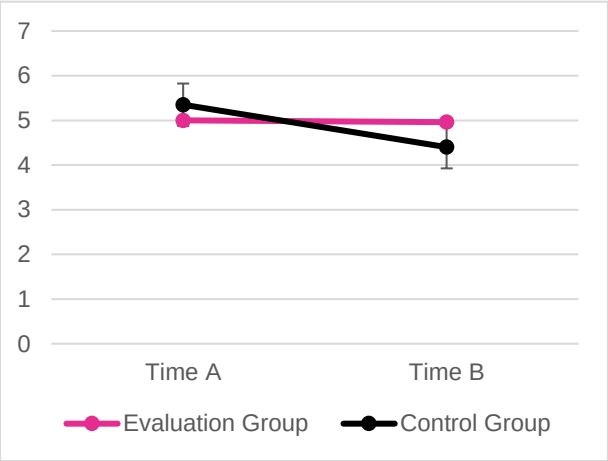


Figure 32. Child Generalised Means

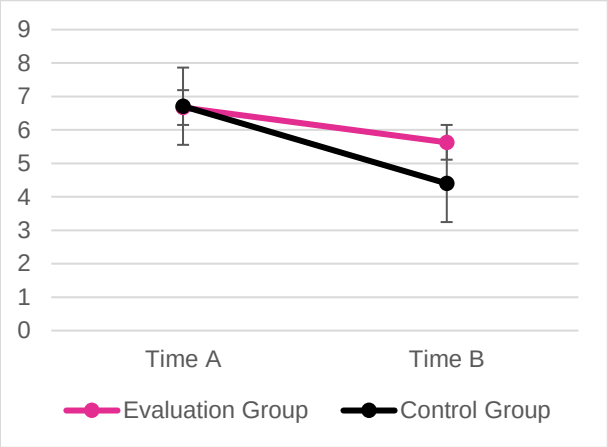


Figure 32. shows that the Obsessive-Compulsive sub-group did not show statistical significance with evaluation group p value *p* = 0.821 and WLC groups 0.308.

In the evaluation group, scores decreased from a mean of 5 (SD = 8.02) at Time A to a mean of 4.95 Time B (SD = 4.49).

For the control group, scores increased from a mean of 5.35 (SD = 7.71) at Time A to a mean of 4.97 at Time B (SD = 4.08).

However, there is a downward trend in the evaluation group, though interestingly an even stronger downward trend in the waitlist group. The Generalised Anxiety means evaluation group p value is p = 0.091, and the control group is 0.874. no statistical significance is found. However, both groups show a downward trend highlighting a decrease in generalised anxiety over time.

Discussion

Findings

The statistical outcomes highlight possible contrasts between the evaluation group and the waitlist control group, specifically, between those who actively participated in the *Flourishing Futures* programme and those awaiting or anticipating participation. These differences in exposure are expected to yield varied outcomes, and the data reflects this divergence.

The findings cautiously suggest that parental participation in *Flourishing Futures* had a beneficial impact on both parents and their autistic children within the timescales assessed.

Analysis revealed some early indications of a reduction in some challenges for autistic children in the evaluation group three months following their parents' participation. Although a general reduction in these challenges was noted across all children, only the evaluation group demonstrated a noticeable (and statistically significant, albeit borderline) improvement. This tentatively suggests that the perspectives, practices, and strategies introduced through the programme may have directly contributed to the observed reductions in recognised challenges.

Reductions in child anxiety were not statistically significant overall though anxiety levels decreased over time in the evaluation group, whereas they increased among waitlist controls. Notably, the Child Social Phobia subscale showed improvement within the evaluation group across the three-month period. This specific finding may cautiously indicate that children experienced increased social confidence or reduced distress in social settings following their parents' participation in the programme. The statistical outcomes portray a contrast between the evaluation group and the waitlist control group, between participation, and waiting for or anticipating participation. Different outcomes are to be anticipated for those reasons.

Whilst overall anxiety levels did not decrease statistically significantly, social anxiety showed a somewhat tentative reduction in the evaluation group. These findings are of particular interest as social anxiety is much higher in autistic children than the non-autistic people. Studies have indicated that up to 50% of young people and adults may have clinically significant social anxiety symptoms. (Spain, Sin, Harwood, Mendez, & Happé, 2017).

In addition to the reductions in social anxiety and some challenges noted among children in the evaluation group, there are some tentative findings across other anxiety subdomains. Notably, the subgroups for *panic attacks* and *separation anxiety* showed a tendency towards decreasing in the evaluation group, while the waitlist control group showed a counter tendency over the same period. This difference cautiously suggests a potential programme-related benefit for these specific forms of anxiety.

Conversely, and again with some caution, there was a slight inclination for a decrease in *physical injury fears*, *social phobia*, *obsessive-compulsive behaviours*, and *generalised anxiety*, all for both groups, tentatively indicating that some reductions in anxiety may occur irrespective of intervention participation. These subdomains may reflect normative developmental processes. According to Autistic Development Theory (ADT), several behaviours associated with autism are understood to emerge at specific stages or phases of development (Lewis & Granic, 2010). As such, the observed changes may, in

part, be indicative of natural developmental transitions rather than solely the result of programme participation.

Findings from the evaluation group indicate a statistically significant decrease in parents' negative experiences, alongside a statistically significant increase in affective balance which is a construct associated with greater overall happiness. The *Flourishing Futures* programme includes targeted strategies designed to support a cognitive rebalancing of attention and emotion (e.g., the "ABC" exercise and the Marble Jar activity). These findings may suggest that parents are focusing less on negative experiences and cultivating a greater sense of emotional well-being as a result of their participation.

While these were the only outcomes to reach statistical significance, other measures showed an early slight inclination towards a positive increase. An exception was *perceived parental stress*, which remained stable in the evaluation group but increased in the waitlist control group. It could be argued that maintaining stable stress levels, particularly in the context of parenting an autistic child, represents a meaningful and positive outcome, especially when contrasted with rising stress levels among those not yet receiving support.

These findings tentatively align with broader literature on parent-mediated interventions for autistic children. For example, a meta-analysis by Nevill et al. (2018) found only small improvements in challenges associate with autism, cognition, and socialisation, and trivial improvements in language and communication. This study found a statistically significant reduction in parent-reported autism challenges and social anxiety, and this is promising given the short programme length and resource-efficient method. A review of 17 trials of parent-mediated interventions found that there was evidence that parental interactions with their autistic child changed to become more observant and responsive (Oono, Honey & McConachie, 2013) and the findings of F.F. may be reflective of this. A strengths-based, parent-mediated approach may provide comparable or enhanced outcomes to other intervention. The increase in parental affective balance and decrease in negative experiences echo findings from positive psychology interventions, which have demonstrated improvements in well-being and emotion regulation among caregivers generally (Seligman et al., 2005; Sin & Lyubomirsky, 2009).

The lack of change in perceived parental stress also mirrors findings in other studies, where stress tends to be more resistant to short-term interventions (Kuhlthau et al., 2014), suggesting that longer-term or multi-layered support may be required. A review of 23 parent-mediated interventions found that parental stress reduced and their well-being increased, though it is not clear of the length of parent training in the interventions that were reviewed (Jurek et al., 2023). However, maintaining stable stress levels in high-demand parenting

environments can be considered a favourable outcome, particularly in contrast to the increased stress observed in the waiting list control group.

Many of the family experiences reported in this study reflect patterns found in existing literature on autism parenting. For example, the importance parents placed on peer support echoes previous findings that shared experiences reduce isolation and build confidence among parents (McConachie & Diggle, 2007; Clifford & Minnes, 2013). Likewise, recruitment challenges and mistrust toward researchers have been noted in other studies, which report that parents of autistic children often experience 'research fatigue' or feel misunderstood by professionals (Pellicano et al., 2014). Emotional shifts observed in parents during workshops, from increased hope to distress when confronting their child's difficulties, have also been documented in studies exploring the emotional journeys of parents in intervention programmes (Kuhn & Carter, 2006). The conflicting feelings between hope and concern were reported by parents in a review of parent-mediated interventions with parents asking for support, especially from peers (Jurek et al., 2023). Acknowledging these commonalities not only situates this study within a well-established body of knowledge but also highlights the potential for Flourishing Futures to offer support with a strengths-based ethos.

Overall, the pilot study findings tentatively suggest that *Flourishing Futures* may produce some beneficial outcomes but further work is needed. These encouraging results provide a case for further research and more extensive evaluation. The Flourishing Futures findings, when compared to those of other programmes, are hopeful and taken with the added value of being time-effective for parents and practitioners and cost-effective for commissioners, further feasibility studies need to be explored.

The following section explores additional insights gained from the study that may guide future development and implementation.

Insights from viewing Flourishing Futures as a Complex Intervention?

When the research outcomes are viewed through the classical or traditional perspective of statistics, results are mixed, largely not statistically significant, with a small number of interesting exceptions.

Respect for the research initiative would argue that its broad intentions have promise, and with the potential for a larger study, more positive data may be found.

Complex interventions are fundamentally systemic in nature, with a range of factors, many or most linked to each other within a 'system'. Families are a 'system' and this perspective would argue that if one promising factor changes, it may yield a ripple effect into other aspects of the system. It could be proposed that with a positive statistical significance

found in the parents' perception of autism symptomology in the child, then there is a systemic movement or change in the family.

It may be that this use of a systemic perspective allows us to look beyond classical statistical measures and persist with further exploration of a means of achieving positive change within the family system. Additionally, when we reflect on the patterns of autism in society and the large and often tragic stress it places on families and individuals, taking the changed perspective of looking at these issues from a systemic perspective is a timely, necessary, and compassionate move.

At this stage, it may be pertinent to share anecdotal experiences with some of the families involved in Flourishing Futures. Two participants from the first evaluation group which was held over three days of workshops, sent 'friend' requests on social media, which were accepted. During the workshops, much discussion took place to create ideas for using their children's interests to enhance their PERMA (Seligman, 2018). One participant's daughter (child 1) was interested in animals and the environment, while the other parent's son (child 2) had an emerging interest in football. It should be noted that child 2 experiences a serious heart condition and engaging in playing the game was not an activity to be pursued. The parent of child 1 decided to join a local nature group with her daughter and child 2's parent chose to take him to see the football. Over the years they have shared their activities on social media, with child 1 regularly litter-picking with a group and generally enjoying nature, and child 2 following his team across the country, watching games and meeting players. Pictures shared on social media of the children enjoying their endeavours show two apparently happy, thriving children, immersed in what they enjoy, and being evermore exposed to the world. The parents have more than embraced the strengths-based approach for over 4 years since participating in the workshops. This is a valuable insight, be it anecdotal, into the long-term utilisation of the approach.

The new framework for complex interventions looks to move beyond answering new specific questions to consider broader questions, such as how it interacts with the context in which it is implemented, how it contributes to change and so on. The anecdotal experiences discussed above may provide some insight into these questions. As previously discussed, the parents of children 1 and 2 attended the 3 days of workshops, which I deemed to have too much time allocated, and decreased to two days of workshops. Their experiences lead to further questions regarding the intervention and timings, have these parents embraced their children's interests so much because they had much more time to explore and play with ideas? Another question that arises from their experiences is that by helping their children engage in their interests, are parents increasing their PERMA too?

Researcher Insights of the Research Journey Generally

As discussed previously, there were challenges in recruiting participants, with some individuals on social media taking offence regarding the wording or even the concept of a new programme. The programme's planning and pragmatic nature enabled a speedy response to adapt wording, for example, referring to 'parent workshops' instead of the previously used 'parent training'.

The research required a high degree of flexibility, with parents from the first group having additional workshops to catch up on missed sessions. Future workshops were offered on both weekdays and weekends to give parents alternative opportunities to attend and to maximise participant recruitment.

The groups quickly appeared relaxed, friendly and open. Considerable changes in some parent's personas from one week to the next were noteworthy. For example, one lady almost bounced in on Day 2, and declared to everyone that she had had '*the best week ever'.*

Concerning the programme's content, parents appeared happy with it, and the discussions were lively and energetic. Parents could apply PP. concepts and come up with ideas that would suit their family and circumstances. The flexibility and adaptability of the programme enabled the inclusion of a wide age range of children and evoked interesting discussions and participation.

Parents appeared to particularly enjoy the videos of the young adults. Some parents commented on the two young adults' video that they appreciated that they were ordinary young people (i.e., not famous or privileged), like their own children. All videos evoked some strong emotions, with the video on Day 2, the strengths-based development video, appearing compelling for some parents, who openly wept. The tears were seen as positive, as the aim was to induce hope, which appeared to occur with these parents.

Two tasks in the programme appeared to be more challenging for parents to engage in; these were the functional skills checklist and the final development plan. Every group responded in the same way to the functional skill checklist, with the room becoming very quiet, and parents appeared to be uncomfortable when they were assessing what tasks their child undertakes for themselves. This may be because the parents realised that their children's functional skills were delayed far more than they realised. Future studies could address this by approaching the functional skill issues in another way rather than the checklist.

There were some interesting responses to the final development plan. Some parents could share ideas and goals that they wanted to focus on but appeared hesitant to write them down on the page. It may be that these parents were not ready to commit themselves to the goals during the workshops or maybe wanted to undertake this with other family members.

The website and forum that was requested by the focus groups were only used a couple of times. Most parents did not request access from the first group, and no parents requested access from any of the following groups. This is interesting as the focus group parents were strongly advocating for these to be made available to them. There could be several reasons for this; the programme may have enabled parents to feel more confident and empowered to be self-reliant and so had no need, or parents used their social media to access peer support from the rest of the group.

Parent feedback was positive, and two examples of follow-up emails are:

> *“Thank you again for the course - I am still applying many of the tips and tricks and S** is responding very well to the increasingly challenging way in which I ask him to respond to teenage situations.”*

> *“Well, how lovely it was to complete the questionnaires. Your workshop really turned things around for me and my son. I've been feeling far more positive, treating everything as a development delay, expecting a little bit more from him and wow, we're making progress* 😊😊😊.”

To summarise, recruitment was extremely challenging and time-consuming, and some parents were suspicious of the research. The workshops' delivery was a positive experience for the parents and me, and the workshops had a friendly atmosphere.

Strengths and Limitations

Parents in the evaluation group generally reported fewer negative experiences and also it can be demonstrated, albeit with some caution given this early work, that there were increases in affective balance. Other than stress, which remained relatively stable, there was a provisional tendency towards positive change for other measures. These findings indicate that Flourishing Futures may tentatively support autistic children's development, decrease social phobias, potentially increase elements of parental well-being, and decrease parental perception of negative experiences. However, further, more extensive investigation is needed.

This study's strength is that it involved participants from diverse geographic areas. There is no national standard for support and education, and parents report a ‘post-code lottery’. The

geographical diversity means that findings are less likely to be skewed by living in a particularly good or lousy region for support and education. A further strength is that the pragmatic approach enabled the design and delivery to be adapted when necessary, such as changing terminology and how many workshops were planned and delivered.

The cost-effectiveness of Flourishing Futures is another key strength. The workshops are held over two days, and this is contrary to most interventions where parents may be taught on a one-to-one basis by a practitioner (Green et al., 2010) or require parents to attend six weekly sessions (Douglas, Sutton, Clarke, Beecham, & Morris, 2010) or twelve weekly sessions (Anan, Warner, McGillivary, Chong, & Hines, 2008) which are costly to provide. Flourishing Futures is a shorter intervention that is cost-effective, that has yielded promising outcomes. Therefore, Flourishing Futures may be more appealing to local authorities and be more accessible to busy families.

The programme length is beneficial to parents who do not have to commit as much time to participate. Interestingly, when Flourishing Futures was cut down from three days to two, parents showed a greater interest. All parents are busy, and parents of autistic children have more pull on their time than other parents, so providing a shorter programme may significantly benefit the autistic community. Having said this, there was increased discussion in the groups who attended for 3 days, especially around strength and interest development. It may be that to balance this in future research, a new forum for discussion could be created and parents encouraged to join.

Flourishing Futures is also highly adaptable to age ranges, which is unusual as most parent programmes are for young children. A meta-analysis of parenting programmes found that of 19 studies for parenting programmes, the age range of children was between 15 to 72 months, with an average age of 42 months. A programme with age flexibility is of great benefit, especially as the diagnosis can be delayed (Rutherford et al., 2016).

One limitation of the research is the difficulty in recruitment and adherence to the programme by completing all of the measures. This is thought to be due to too many measures being used. The recruitment difficulties may have contributed to statistical tests being underpowered for significance. There was an expectation that Flourishing Futures would make a difference to parents and children, though being unique, it was an unknown in what domains the programme may benefit parents and autistic children. In respect of this, the measures for children were the ATEC, that considers autism symptomology in several domains and was developed to be used by researchers. The second child measure was the SPENCE child anxiety scale, which was chosen due to the high rates of child anxiety being

reported. There were also a number of adult scales for parents, and in future projects these may be reduced and this may help with recruitment and adherence.

Another limitation is the sample size of the evaluation and control groups, which, alongside missing data, led to the use of non-parametric statistical tests for evaluation. Whilst some results are positive, the group size and tests used should lead to caution interpreting results. A further limitation is that Flourishing Futures has a lot of content and strategies and it is not clear which aspects of the programme are leading to the effects, or alternatively if it is the whole programme that is having an impact. The small sample size meant that potentially valuable analysis could not occur, for example, evaluating the impact for different age ranges and those with comorbid conditions.

A further limitation is the lack of socio-demographic information, which could have further enhanced understanding of variables on outcomes, such as parental education.

The programme was evaluated over three months, and this short time scale adds further limitations to the study, as long-term effects are not known. The long-term effects of participation would be a valuable next step in a future study.

Conclusion and Next Steps

This preliminary study, of a parent-mediated, strengths-based intervention for autistic children, has yielded promising results. Flourishing Futures provides a rather cautious early indication of change in parent's perceived symptoms of autism over three months in the evaluation group. Whilst not statistically significant, child anxiety decreased over time after parental participation in the programme, in contrast to the waitlist control groups who showed increased anxiety over time. The changes found in the children's mean scores with regards to social phobia may be due to the change in the parent's perception of negative experiences. Future evaluations could use an independent assessor to complete the questionnaires.

A meta-analysis of parent-mediated interventions found only small improvements in cognition and socialisation and 'trivial' improvements in language and communication skills (Nevill, Lecavalier, & Stratis, 2018 p. 12). The Flourishing Futures findings are noteworthy, especially when compared to those of other programmes and the added value of being time-effective for parents and practitioners and cost-effective for commissioners.

It could be cautiously postulated that engagement with Flourishing Futures may have shifted parental perceptions. It could, therefore, be tentatively proposed that this shift in itself may have led to perceived changes in their own children's autism and social anxiety. This shift could be considered as one to the family system, and this changed the context for the

child, enabling growth and development. As previously discussed, autism can be viewed as a complex problem, requiring a complex intervention. However, rather than being deficit-driven and seeing the problem as within the child, Flourishing Futures used a strengths-based approach, adopting the spaces of well-being ethos (Atkins, 2013) to help parents understand their children in context. This may have been a significant contributory factor in the positive outcomes of the research.

Had the Skivington et al. framework been available during the planning stages, several aspects of the study design may have been approached differently. A greater emphasis would have been placed on formal feasibility outcomes, including recruitment processes, retention rates, and the acceptability of the intervention to participants. While the study incorporated feedback from parents from the focus groups during the development process, systematic evaluation of these feasibility elements was not a primary focus. Future work should address these aspects more explicitly to ensure that the intervention is not only theoretically sound but also practical and acceptable in real-world settings.

To strengthen the future development and implementation of the intervention, a formal feasibility study is recommended. This may include a structured assessment of recruitment strategies, participant engagement and retention, and perceived acceptability of both the content and delivery of the intervention. Such data will be essential in informing the refinement of the intervention and determining its readiness for larger-scale evaluation.

This study's findings provide support for a larger scale feasibility study and provide valuable insights that can be used to inform future studies. The next chapter will discuss ideas for the next steps for Flourishing Futures, the APT and ADT.

CHAPTER EIGHT

DISCUSSION AND CONCLUSIONS

INTRODUCTION

This chapter brings together findings from the literature review, focus groups, theoretical development and intervention evaluation. These are to address the overarching aim of this work which was to develop a parent-mediated, strengths-based intervention that supports the well-being and development of autistic children and their families. This chapter is structured around the key research questions and shows how each has been answered, highlighting how the research contributes to theoretical understanding and practical applications.

In doing so, the chapter aims to contextualise the study's findings within existing literature, articulate the original contributions of the Adapted Phenotype Theory (APT) and Autistic Development Theory (ADT), and critically reflect on the implications. By situating the findings in a broader developmental and evolutionary context, the chapter challenges traditional deficit-focused models of autism and offers a reframing that emphasises potential for development and well-being.

Initially this chapter revisits the original research aims and questions, synthesises findings from across the study, and discusses the theoretical and practical implications of the research. It introduces critical reflections on the research process and concludes with proposals for future research and practice.

Revisiting the Research Aims

The study aimed to understand the factors contributing to mental health difficulties in autistic individuals and to develop and evaluate a parent-mediated, strengths-based intervention Flourishing Futures. The core research questions were:

1. What are the key factors contributing to the mental health difficulties experienced by autistic individuals?
2. How can a strengths-based, parent-mediated intervention be designed to support autistic children and their families?
3. What is the impact of the intervention, Flourishing Futures, on autistic children's well-being and development and on parent well-being?
4. How do APT and ADT contribute to existing understandings of autism and its heterogeneity of developmental trajectories?

Research Question 1: What are the key factors contributing to the mental health difficulties experienced by autistic individuals?

The study identified a complex interplay of biological, environmental, and social factors that are associated with the mental health challenges that may be experienced by autistic individuals. The literature review and focus group findings highlighted the prevalence of anxiety and depression among autistic individuals and highlighted sensory sensitivity and environmental mismatches as contributors to this.

The Adapted Phenotype Theory (APT) proposes autism is an adaptive response to maternal stress, involving alterations in the SC and HPA axis in the foetus. This novel theory contextualises heightened threat sensitivity and hyper-reactivity within an evolutionary framework, offering a deeper explanation for the observed high stress and anxiety found within the population.

Autistic Development Theory (ADT) proposes that these adaptations disrupt early developmental processes, such as dyadic interactions with caregivers which may lead to delays in the domains of social interaction and communication. These may compound stress and this may provide a possible challenge for developmental progression, particularly when the environment and supports are misaligned with individual needs. ADT identifies various factors that may influence development either positively or negatively. Within ADT is the acknowledgement that many behavioural or cognitive presentations that are considered ‘autistic’ are typical developmental presentations or behaviours that may occur chronologically later in autistic children and therefore appear pathological.

The answers to this Research Question have contributed to knowledge by concluding that APT and ADT position autism, not as a deficit, but as an adaptation to the expected post-natal environment with developmental implications in modernity. This approach encourages contextual and developmental approaches to support and interventions for autistic individuals and their families.

Research Question 2: How do APT and ADT contribute to existing understandings of autism and its developmental trajectories?

APT and ADT provide developmental and evolutionary models that account for observed heterogeneity in autistic traits and outcomes. These theories unify disparate strands of research across biology, psychology, and education, offering a more comprehensive understanding of the phenotype and various factors that may influence development in modernity.

The Adapted Phenotype theory proposes that the traits associated with autism can be understood as part of a naturally occurring cognitive and behavioural variation, rather than as deficits or disorders. This perspective emphasises that the Superior Colliculus and HPA axis is enhanced as an adaptive response to environmental pressures leading to maternal stress. In an environment that is supportive and not overstimulating to the SC and HPA axis, the enhancements and hyper-plasticity can become a strength for the individual. The theory supports a neurodiversity paradigm, encouraging greater acceptance and inclusion of autistic individuals by recognising their unique strengths and contributions.

The theoretical contributions to knowledge include: The Adapted Phenotype Theory is an ultimate (why) explanation of autism's evolutionary basis, using current scientific evidence to propose that maternal stress during pregnancy may lead to epigenetic changes in pre-disposed foetuses, adapting them for the expected post-natal environment.

ADT is considered a proximate (how) explanation using a developmental framework and may be used to inform parental, educational, social, and clinical support. ADT acknowledges that several presentations that have previously appeared to be stable characteristics of autism are developmental in nature and therefore transitory.

Research Question 3: How can a strengths-based, parent-mediated intervention be designed to support autistic children and their families?

The intervention, Flourishing Futures, was developed using insights from focus groups, positive psychology literature and practice and Autistic Development Theory. Components included strategies to reduce environmental stressors, minimise the effects of stress, to plan for and guide developmental progress, and promote family well-being using a strengths-based approach.

Parents welcomed the strengths-based ethos, and the intervention was unique for being suitable for different developmental stages and accommodating the varied experiences of families across child age ranges.

This research contributes an intervention that is contextually responsive, and theory informed. Many interventions are aimed at supporting young autistic children and uniquely, Flourishing Futures can be provided to a diverse age range. It also demonstrates how positive psychology can be adapted to serve neurodiverse populations through family-focused delivery of a strengths-based approach.

Research Question 4: What is the impact of the intervention (Flourishing Futures) on autistic children's well-being and development, and on parent well-being?

The outcomes of the pilot tentatively indicate improvements in parental affective balance and reductions in children's autism symptoms and social anxiety (though it should be noted these are parental self-reports). Though broader anxiety measures showed limited statistical change, there are some positive benefits reported by parents though these benefits are not reported as statistically significant trends and so a treated with caution.

Compared to meta-analyses of other parent-mediated interventions (Nevill et al., 2018), Flourishing Futures appears to show promise that with further foundational work, it may be possible to attain enhanced outcomes for autistic children using a strengths-based approach.

The study provides preliminary evidence that reframing parental perception and family dynamics may – with further work – yield measurable changes in child well-being, supporting the value of systems-level, strengths-based interventions.

Strengths, Limitations, and Future Directions

A strength of this work is the development of two novel theories (APT and ADT), based on current scientific evidence, contributing to theoretical understanding of autism. Whilst the theories are separate, they are highly complementary. By offering the two separate theories means that in the future they may be evaluated in several ways, from observational studies to stress markers in blood.

The integration of positive psychology with autism research represents a relatively novel and promising approach. Traditionally, the fields of autism and positive psychology have remained largely separate, however, recent discussions, such as those highlighted by Wright et al. (2024). have drawn attention to this gap, noting that there has been minimal conceptual or empirical overlap between the two disciplines. This emerging integration seeks to reframe how autism is understood, moving beyond a purely deficit-based model to one that also acknowledges and harnesses strengths, and builds the well-being of autistic individuals. It opens new routes for research and practice that prioritise quality of life, self-determination, and positive identity development in autistic individuals. Therefore, a significant strength of this work is that it meets the calls for the focus of research and practice in the merging of the two disciplines.

The parental consultation regarding Flourishing Futures with parents ensured that it was tailored to the needs of families. By involving parents in the development process as a result of consultation, Flourishing Futures was accessible and sustainable. The practical, scalable design of Flourishing Futures means that with the rising rates of autism diagnosis there is promise of an affordable intervention that puts parents at the heart of their child's support.

Limitations

A limitation is the small sample size and short evaluation period of Flourishing Futures, with only a three-month follow up. Future feasibility studies may lengthen the evaluation period which could provide further insight into any highlighted areas with potential for development. Potentially there could be an extended evaluation period of 6–12 months and the use of mixed methods (e.g., observational data, biological markers for stress).

The reliance on parent-reported outcomes is a further limitation – it is not clear for example if the significance found in the social anxiety measure was the child experiencing less anxiety, or a change in the parent's perception of the child's anxiety. Future evaluations could incorporate the use of independent judges to provide a potentially more robust process.

Future Research

There are various possibilities for further research. It is possible to test the neurobiological validation of APT, for example through studies that use *f* MRI to consider the activation of the SC.

A longitudinal study could be a valuable method for assessing the sustained impact of the Flourishing Futures intervention over time. By following participants longitudinally, researchers would be able to evaluate not just immediate changes, but also if the intervention influences long-term developmental trajectories, mental health, academic outcomes, and quality of life. Such studies could provide insights into whether any potential gains in areas well-being are maintained, enhanced, or diminish over time. Additionally, a longitudinal design may identify any delayed effects, unintended consequences, or interactions with other life events and transitions, especially those of schooling, refining the intervention based on long-term data.

Comparative studies could assess the relative effectiveness of Flourishing Futures in relation to other established intervention models used with autistic children and young people. This might include comparisons with approaches such as EarlyBird (Palmer et al., 2019). These studies could use randomized controlled trials (RCTs) or matched-group designs to evaluate outcomes across different domains, for example communication and well-being.

Further exploration into the potential overlap between autism, giftedness, and highly sensitive people could enrich understanding of neurodivergent profiles and help tailor the Flourishing Futures model. Investigating these overlaps could inform more nuanced approaches that recognise and support both challenges and exceptional abilities. This

approach may challenge deficit-based stereotypes by highlighting strengths that are often overlooked or misunderstood. Relatedly, the research conclusions could further help ensure that Flourishing Futures meets the needs of children who may not fit conventional profiles but still benefit from a strengths-based, personalised approach.

Conclusion

This research contributes new understanding to the field of autism by proposing two original theories, developing an innovative parent-mediated intervention, and providing evidence of its early impact. By adopting a strengths-based, developmentally sensitive approach, it challenges dominant deficit models and offers a possible framework for supporting autistic children and their families that would benefit from further evaluation.

Future research may aim to further validate the theoretical contributions, replicate and expand the intervention evaluation, and engage with wider policy and practice to ensure that the needs and potential of autistic individuals are better understood and supported.

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Appendix A

Ethics Panel: Participant Information and Consent

Dear (name),

I am a PhD student at Buckinghamshire New University and have been researching autism and co-morbid mental health problems.

The research has led to the development of a novel approach to understanding autism. Alongside this, we have developed a new parenting programme with an aim to improve outcomes and wellbeing for autistic children and their families.

The programme has also been informed by parents who participated in focus groups.

I am contacting you as we are looking for families to participate in the programme and evaluation.

The parent workshops will be run over three days, over three consecutive weeks.

Parents from the focus groups asked for involvement of the wider family and online support and resources. In response to this, the programme will be uploaded to a website for other family members to watch and there will be a private forum for support and to ask questions.

I have attached a flyer for parents and would be grateful if you would email to parents whom you support.

If you have any questions, please get in touch using this email address.

Thank you in advance.

Ruth Howard

Supervisors: Dr Piers Worth; Dr Matthew Smith; Professor Colin Martin

Appendix B

Recruitment Flyer

Flourishing Futures

Strengths Based Autism Parenting

Are you the parent of an autistic child aged between 2yrs and 11yrs?

Would you like to participate in autism research?

Would you like to know about a new theory of autism?

The Research

We have developed a new autism parenting programme based on strengths-based parenting and a new theory of autism.

We are looking for local parents to join us for three days to learn about this new approach and how to use it with your child.

The research will continue for 3 months and participants will have access to a website, an online forum and resources.

Your whole family will be able to access the site and watch the programme online.

If you are interested, please get in touch with the lead researcher using the email below and we will send you more information:

Ruth.Howard@bucks.ac.uk

Research Team: Ruth Howard, Dr Piers Worth, Dr Matthew Smith, Professor Colin Martin

Appendix C

Participant Information Evaluation Group

PARTICIPANT INFORMATION SHEET
Flourishing Futures Autism Parenting Programme

You are being invited to take part in a research project. Before you decide whether you want to take part it is important for you to understand why the research is being done and what it will involve. Please take the time to read the following information carefully.

Who is conducting the research?
This project is being conducted by Ruth Howard as part of her PhD at Buckinghamshire New University.

What is the purpose of the study?
This research is to evaluate the impact of a new parenting programme on autistic children and their caregivers.

The programme (Flourishing Futures) is based on a new model of autism, autistic development theory (ADT). ADT provides understanding and support for the individual child's unique presentation and the impact of environmental influences.
Flourishing Futures aims to:

- Empower participants to cope and decrease their stress, to enhance their well-being and ability to support their child through difficulties and improve developmental progress.

- Enable participants to respond to the child from the perspective of ADT, adapt parenting style and sensory stimuli to decrease sensory overload and anxiety to improve development.

- Provide participants with the knowledge and skills to employ a parenting style that focuses on developing children's strengths and talents.

- Use adapted positive psychology interventions to support well-being and resilience for the whole family.

What is involved in participating?
Participants will be asked to complete some short questionnaires for themselves and their autistic child before the workshops. There are two questionnaires for parents to complete for their children and four for parents to complete for themselves. Completing the questionnaires should take approximately 30 minutes.

Participants will attend 3 workshops, held on weekdays. After the final workshop participants will be asked to complete the questionnaires again.

The workshop slides will be uploaded onto a website to enable other family members to watch should they wish to.

Participants will be given access to an on-line private forum. This forum is to stay in touch with each other, give each other support and ask questions. The lead researcher (Ruth Howard) will monitor the forum and answer questions.

After 3 months, there will be a get together to share experiences and you will be asked to complete the short questionnaires again.

Why have I been invited to participate?
You have been invited to take part as you are a parent of an autistic child between the ages of 2-11years.

Do I have to take part?
No. It is up to you to decide whether to take part as participation is entirely voluntary. If you do decide to take part you will be asked to indicate on the questionnaire that you have read this and give consent to take part.

You may also choose to withdraw from activities during the workshops if you do not want to take part.

You are still free to withdraw at any time, before the data are analysed from 30th April 2019 and without giving a reason.

What are the possible benefits and risks of taking part?
Benefits of taking part in this study include aiding research into the understanding of autism and a new parenting programme. The main beneficiary of the study is the researcher, who will use the data for a PhD thesis. No risks are anticipated in taking part in this study.

Will what I say or do in this study be kept confidential?
You will be asked to give your name so that we are able to find if the measures show any differences across time. The information will be anonymised by allocation of a personal identifier. Only the researcher and her supervisor will have access to the data, which will be stored by the researcher in accordance with the Buckinghamshire New University policy on data security. The anonymised data will be used for a PhD thesis and may form part of a published article and/or conference/seminar paper. The data generated in the course of the research will be likely to be used for a publication and/or conference/seminar paper, it will be transferred to the supervisor and kept for a period of ten years after the completion of the research project.

Who has reviewed the study?
This study has been approved by the Research Ethics Committee at Buckinghamshire New University.

The researcher will conduct the research in accordance with Buckinghamshire New University safeguarding policies which can be accessed using the link: https://bucks.ac.uk/__data/assets/pdf_file/0010/13132/Safeguarding-Under-18s-and-Adults-at-Risk-Policy.pdf

If you have any additional questions regarding this study, please contact either:
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Below is a list of organisations that you may also seek support from:

Leicestershire Autistic Society:	https://www.leicestershireautisticsociety.org.uk/
Autism East Midlands:	https://www.autismeastmidlands.org.uk
Autism West Midlands:	https://www.autismwestmidlands.org.uk
Coventry Action for Autism Group:	Kellie: 024 7668 8521 or Mary: 024 7622 2958
The National Autistic Society:	https://www.autism.org.uk

Thank you for taking time to read this information.

INFORMED CONSENT FORM

Flourishing Futures Parenting Programme

Please initial box

I confirm that I have read and understand the Participant Information Sheet for the above study and have had the opportunity to ask questions. ☐

I understand that taking part in the project will involve completing some questionnaires for myself and my child, participating in 3 days of workshops and an on-line forum for 3 months after the workshops. ☐

I understand that my participation is voluntary and that I am free to withdraw at any time up until the point the data are analysed from 30th April 2019, without giving reason. ☐

I agree to take part in the above study. ☐

I agree that my data gathered in this study may be stored (after it has been anonymised) in a specialist data centre and may be used for future research; and that any researcher who has access to these data may only do so if they agree to preserve the confidentiality of these data. ☐

Please tick box

	Yes	**No**
I agree to the workshops being video recorded.	☐	☐

Name of Participant	Date	Signature

Name of Researcher	Date	Signature

One copy to be kept by the participant, one to be kept by the researcher

Flourishing Futures
Participant Application Form

If you would like to apply to participate in the research, please complete this form and return to the lead researcher via email: Ruth.Howard@bucks.ac.uk.
If you have any questions, please contact the lead researcher using the email above.

Contact Details of Participant
Parent/Caregiver Name: _____

Contact Email: _____

Address: _____

_____

Contact Number: _____

Will you be participating in another parenting programme in the next 6 months?
Yes No

Please complete the child information below **for your child or children who have a diagnosis of autism**.

1st Child Information:
Current Age: Age at Diagnosis: Autism Diagnosis:

Does your child have any other diagnosed conditions? Yes No

If yes, please list the conditions below:

_____
_____
_____
_____

Is your child currently being prescribed medication? Yes No

If yes, please list the medications below:

_____
_____
_____
_____

2nd Child Information:

Current Age: Age at Diagnosis Autism Diagnosis

Does your child have any other diagnosed conditions? Yes No

If yes, please list the conditions below:

Is your child currently being prescribed medication? Yes No

If yes, please list the medications below:

3rd Child Information:

Current Age: Age at Diagnosis Autism Diagnosis

Does your child have any other diagnosed conditions? Yes No

If yes, please list the conditions below:

Is your child currently being prescribed medication? Yes No

If yes, please list the medications below:

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the UK Data Protection Act 1998.

Tick box if you consent: ☐

Signed: Print Name: Date:

Please return completed form to: Ruth.Howard@bucks.ac.uk

Appendix F Ethics: Adult and Child Measures

The following appendices are the measurement tools to be used for statistical analysis.
For parents to complete for their children:

- SPENCE children's anxiety scale (parent report).

  The key outcome of this programme a decrease in children's anxiety. This scale will be used for parents to report on their children's anxiety to evaluated pre and post intervention.

- The Autism Treatment Evaluation Checklist (Mahapatra et al., 2018).

  This measure was developed to assess the effectiveness of autism treatment. It is proposed that the potential decreased anxiety in children will lead to a decrease in some behaviours associated with autism.

  It is also proposed that the programme will lead to greater understanding of the individual child's needs and developmental potential thus leading to development in areas of delay associated with autism.

For parent participants these are:

- Scale of Positive and Negative Experience (SPANE) (Diener et al., 2010) & The Flourishing Scale (Diener et al., 2010).

  These measures have been developed to use to assess psychological flourishing. The intervention has been designed to help parents utilise positive psychology practices and these measures will in part assess the effectiveness.

- The Adult Trait Hope Scale (Snyder et al., 1991).

  It is expected that by decreasing uncertainty about the future and giving insight into adult life, alongside strategies to support their child with difficulties and development, parents will become more hopeful post intervention.

- The Flourishing Scale (Diener and Biswas-Diener 2009).

  The flourishing scale is an 8 item measure of self-perceived success and provides a score of psychological well-being.

- The Perceived Stress Scale (S. Cohen et al., 1983).

  This will be used to determine whether the intervention affected the perceived stress that parents feel.

SPENCE CHILDREN'S ANXIETY SCALE (Parent Report)

Your Name: Date: Your Child's Name:

BELOW IS A LIST OF ITEMS THAT DESCRIBE CHILDREN. FOR EACH ITEM PLEASE CIRCLE THE RESPONSE THAT BEST DESCRIBES YOUR CHILD. PLEASE ANSWER ALL THE ITEMS.

1. My child worries about things..... Never Sometimes Often Always
2. My child is scared of the dark..... Never Sometimes Often Always
3. When my child has a problem, s(he) complains of having a funny feeling in his / her stomach ..... Never Sometimes Often Always
4. My child complains of feeling afraid..... Never Sometimes Often Always
5. My child would feel afraid of being on his/her own at home.....Never Sometimes Often Always
6. My child is scared when s(he) has to take a test..... Never Sometimes Often Always
7. My child is afraid when (s)he has to use public toilets or bathrooms. Never Sometimes Often Always
8. My child worries about being away from us / me..... Never Sometimes Often Always
9. My child feels afraid that (s)he will make a fool of him/herself in front of people..... Never Sometimes Often Always
10. My child worries that (s)he will do badly at school..... Never Sometimes Often Always
11. My child worries that something awful will happen to someone in our family..... Never Sometimes Often Always
12. My child complains of suddenly feeling as if (s)he can't breathe when there is no reason for this..... Never Sometimes Often Always
13. My child has to keep checking that (s)he has done things right (like the switch is off, or the door is locked).. ..... Never Sometimes Often Always
14. My child is scared if (s)he has to sleep on his/her own..... Never Sometimes Often Always
15. My child has trouble going to school in the mornings because (s)he feels nervous or afraid..... Never Sometimes Often Always
16. My child scared of dogs ..... Never Sometimes Often Always
17. My child can't seem to get bad or silly thoughts out of his / her head..... Never Sometimes Often Always
18. When my child has a problem, s(he) complains of his/her heart beating really fast..... Never Sometimes Often Always
19. My child suddenly starts to tremble or shake when there is no reason for this..... Never Sometimes Often Always
20. My child worries that something bad will happen to him/her.....Never Sometimes Often Always
21. My child is scared of going to the doctor or dentist ..... Never Sometimes Often Always
22. When my child has a problem, (s)he feels shaky..... Never Sometimes Often Always
23. My child is scared of heights (eg. being at the top of a cliff)..... Never Sometimes Often Always
24. My child has to think special thoughts (like numbers or words) to stop bad things from happening..... Never Sometimes Often Always
25. My child feels scared if (s)he has to travel in the car, or on a bus or train ..... Never Sometimes Often Always
26. My child worries what other people think of him/her..... Never Sometimes Often Always
27. My child is afraid of being in crowded places (like shopping centres, the movies, buses, busy playgrounds)..... Never Sometimes Often Always
28 All of a sudden my child feels really scared for no reason at all..... Never Sometimes Often Always

29. My child is scared of insects or spiders..... Never Sometimes Often Always
30. My child complains of suddenly becoming dizzy or faint when
there is no reason for this..... Never Sometimes Often Always
31. My child feels afraid when (s)he has to talk in front of the class..... Never Sometimes Often Always
32. My child's complains of his / her heart suddenly starting to
beat too quickly for no reason ..... Never Sometimes Often Always
33. My child worries that (s)he will suddenly get a scared feeling
when there is nothing to be afraid of..... Never Sometimes Often Always
34. My child is afraid of being in small closed places,
like tunnels or small rooms..... Never Sometimes Often Always
35. My child has to do some things over and over again (like washing
his / her hands, cleaning or putting things in a certain order)..... Never Sometimes Often Always
36. My child gets bothered by bad or silly thoughts or pictures
in his/her head ..... Never Sometimes Often Always
37. My child has to do certain things in just the right way to stop
bad things from happening ..... Never Sometimes Often Always
38. My child would feel scared if (s)he had to stay away from
home overnight..... Never Sometimes Often Always
39. Is there anything else that your child is really afraid of? ..... YES NO

Please write down what it is, and fill out how often (s)he is afraid of this thing:

Never Sometimes Often Always

2000 Susan H. Spence

4182 Adams Avenue, San Diego, CA 92116
fax: (619) 563-6840; www.autism.com/ari

This form is intended to measure the effects of treatment. Free scoring of this form is available by mailing or faxing this sheet to ARI or at our website at: www.autism.com/atec

Name of Child _____ _____ [ ] Male Age ___ Last First [ ] Female Date of Birth ____
Form Completed by_____ Relationship_____ Today's Date ____

Please circle the letters to indicate how true each phrase is:

I. Speech/Language/Communication

[N] Not true [S] Somewhat true [I/] Very true

N S V I. Knows own name
N S V 2. Responds to 'No' or 'Stop'
N S V 3. Can follow some commands
N S V 4. Can use one word at a time (No!, Eat, Water, etc.)
N S V 5. Can use 2 words at a time (Don't want, Go home)
N S V 6. Can use 3 words at a time (Want more milk)
N S V 7. Knows 10 or more words
N S V 8. Can use sentences with 4 or more words
N S V 9. Explains what he/she wants
N S V 10. Asks meaningful questions
N S V 11. Speech tends to be meaningful/ relevant
N S V 12. Often uses several successive sentences
N S V 13. Carries on fairly good conversation
N S V 14. Has normal ability to communicate for his/her age

II. Sociability:

[N] not descriptive [S] Somewhat descriptive [V] Very descriptive

N S V 1. Seems to be in a shell - you cannot reach him/her
N S V 2. Ignores other people
N S V 3. Pays little or no attention when addressed
N S V 4. Uncooperative and resistant
N S V 5. No eye contact
N S V 6. Prefers to be left alone
N S V 7. Shows no affection
N S V 8. Fails to greet parents
N S V 9. Avoids contact with others
N S V 10. Does not imitate
N S V 11. Dislikes being held/cuddled
N S V 12. Does not share or show
N S V 13. Does not wave 'bye bye'

N S V 14. Disagreeable/not compliant
N S V 15. Temper tantrums
N S V 16. Lacks friends/companions
N S V 17. Rarely smiles
N S V 18. Insensitive to other's feelings
N S V 19. Indifferent to being liked
N S V 20. Indifferent if parent(s) leave

III. Sensory /Cognitive Awareness:

[N] Not descriptive [S] Somewhat descriptive [V] Very descriptive
N S V 1. Responds to own name
N S V 2. Responds to praise
N S V 3. Looks at people and animals
N S V 4. Looks at pictures (and T.V.)
N S V 5. Does drawing, coloring, art
N S V 6. Plays with toys appropriately
N S V 7. Appropriate facial expression
N S V 8. Understands stories on T.V.
N S V 9. Understands explanations
N S V 10. Aware of environment
N S V 11. Aware of danger
N S V 12. Shows imagination
N S V 13. Initiates activities
N S V 14. Dresses self
N S V 15. Curious, interested
N S V 16. Venturesome - explores
N S V 17. "Tuned in" — Not spacey
N S V 18. Looks where others are looking

IV. Health/Physical/Behaviour:
Use this code: [N] Not a Problem [MI] Minor Problem [MO] Moderate Problem [S] Serious Problem
N MI MO S 1. Bed-wetting
N MI MO S 2. Wets pants/diapers
N MI MO S 3. Soils pants/diapers
N MI MO S 4. Diarrhea
N MI MO S 5. Constipation
N MI MO S 6. Sleep problems
N MI MO S 7. Eats too much/too little
N MI MO S 8. Extremely limited diet
N MI MO S 9. Hyperactive
N MI MO S 10. Lethargic
N MI MO S 11. Hits or injures self
N MI MO S 12. Hits or injures others

N MI MO S 13. Destructive
N MI MO S 14. Sound-sensitive
N MI MO S 15. Anxious/fearful
N MI MO S 16. Unhappy/crying
N MI MO S 17. Seizures
N MI MO S 18. Obsessive speech
N MI MO S 19. Rigid routines
N MI MO S 20. Shouts or screams
N MI MO S 21. Demands sameness
N MI MO S 22. Often agitated
N MI MO S 23. Not sensitive to pain
N MI MO S 24. "Hooked" or Fixated on certain objects/topics
N MI MO S 25. Repetitive movements (stimming, rocking)

The Trait Hope Scale

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1. = Definitely False 2. = Mostly False 3. = Somewhat False 4. = Slightly False 5. = Slightly True 6. = Somewhat True 7. = Mostly True 8. = Definitely True

1. I can think of many ways to get out of a jam. ___
2. I energetically pursue my goals. ___
3. I feel tired most of the time. ___
4. There are lots of ways around any problem. ___
5. I am easily downed in an argument. ___
6. I can think of many ways to get the things in life that are important to me. ___
7. I worry about my health. ___
8. Even when others get discouraged, I know I can find a way to solve the problem. ___
9. My past experiences have prepared me well for my future. ___
10. I've been pretty successful in life. ___
11. I usually find myself worrying about something. ___
12. I meet the goals that I set for myself.

Note. When administering the scale, it is called The Future Scale. The agency subscale score is derived by summing items 2, 9, 10, and 12; the pathway subscale score is derived by adding items 1, 4, 6, and 8. The total Hope Scale score is derived by summing the four agency and the four pathway items.

FLOURISHING SCALE

©Copyright by Ed Diener and Robert Biswas-Diener, January 2009

Below are 8 statements with which you may agree or disagree. Using the 1–7 scale below, indicate your agreement with each item by indicating that response for each statement.

• 7 - Strongly agree • 6 - Agree • 5 - Slightly agree • 4 - Neither agree nor disagree • 3 - Slightly disagree • 2 - Disagree • 1 - Strongly disagree

____ I lead a purposeful and meaningful life
____ My social relationships are supportive and rewarding
____ I am engaged and interested in my daily activities
____ I actively contribute to the happiness and well-being of others
____ I am competent and capable in the activities that are important to me
____ I am a good person and live a good life
____ I am optimistic about my future
____ People respect me

Scoring:

Add the responses, varying from 1 to 7, for all eight items. The possible range of scores is from 8 (lowest possible) to 56 (highest PWB possible). A high score represents a person with many psychological resources and strengths.

Scale of Positive and Negative Experience (SPANE)

© Copyright by Ed Diener and Robert Biswas-Diener, January 2009.

Please think about what you have been doing and experiencing during the past four weeks. Then report how much you experienced each of the following feelings, using the scale below.

For each item, select a number from 1 to 5, and indicate that number on your response sheet.

1. Very Rarely or Never
2. Rarely
3. Sometimes
4. Often
5. Very Often or Always

Positive
Negative
Good
Bad
Pleasant
Unpleasant
Happy
Sad
Afraid
Joyful
Angry
Contented

Scoring: The measure can be used to derive an overall affect balance score, but can also be divided into positive and negative feelings scales.

Positive Feelings (SPANE-P): Add the scores, varying from 1 to 5, for the six items: positive, good, pleasant, happy, joyful, and contented. The score can vary from 6 (lowest possible) to 30 (highest positive feelings score).

Negative Feelings (SPANE-N): Add the scores, varying from 1 to 5, for the six items: negative, bad, unpleasant, sad, afraid, and angry. The score can vary from 6 (lowest possible) to 30 (highest negative feelings score).

Affect Balance (SPANE-B): The negative feelings score is subtracted from the positive feelings score, and the resultant difference score can vary from -24 (unhappiest possible) to 24 (highest affect balance possible). A respondent with a very high score of 24 reports that she or he rarely or never experiences any of the negative feelings, and very often or always has all of the positive feelings.

Perceived Stress Scale- 10 Item

(S. Cohen et al., 1983)

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, please indicate with a check how often you felt or thought a certain way.

1. In the last month, how often have you been upset because of something that happened unexpectedly?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

2. In the last month, how often have you felt that you were unable to control the important things in your life?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

3. In the last month, how often have you felt nervous and "stressed"?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

4. In the last month, how often have you felt confident about your ability to handle your personal problems?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

5. In the last month, how often have you felt that things were going your way?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

6. In the last month, how often have you found that you could not cope with all the things that you had to do?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

7. In the last month, how often have you been able to control irritations in your life?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

8. In the last month, how often have you felt that you were on top of things?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

9. In the last month, how often have you been angered because of things that were outside of your control?___
   0=never___1=almost never___2=sometimes___3=fairly often___4__very often

10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?___
    0=never___1=almost never___2=sometimes___3=fairly often___4__very often

Participant Joining Instructions

Flourishing Futures Workshops

Welcome to the Flourishing Futures Autism parenting research. We are delighted to have you participate in our research and look forward to meeting you.

Below are the details of the workshops, if you have any questions, please contact me using the email below.

Dates: *****

Time: 9.15am – 3pm

Venue: ******

Refreshments: Refreshments will be available throughout the day.

Lunch: Please bring your lunch with you.

Best wishes,

Ruth Howard

Strengths Based Autism Parenting Research

Consent Form: Autistic Young Adult Contributors

Flourishing Futures: Strength Based Autism Parenting Research

Please tick the following:

I have read and understood the project information sheet. ☐

I have been given the opportunity to ask questions about the project. ☐

I agree to take part in the project. ☐

I agree to be filmed for the course and agree to the film being published online. ☐

I understand that my taking part is voluntary. I can withdraw from the study at any time and I will not be asked questions about why I no longer want to take part. ☐

I understand that once published, it may not be possible to remove my video from the course ☐

I understand my personal details such as phone number or address will not be revealed to people outside of this project. ☐

I understand that my words may be quoted in publications, reports, web pages, and other research outputs. ☐

I understand that other researchers will have access to these data only if they agree to preserve the confidentiality of these data. ☐

I understand that other researchers may use my words in publications, reports, web pages and other research outputs. ☐

On this basis I am happy to participate in the Flourishing Futures study. ☐

Name of Participant …… Signature……Date……

Name of Researcher Ruth Howard

Signature……Date……

.

If you have any queries or concerns, please contact: Ruth.Howard@bucks.ac.uk; Piers.Worth@bucks.ac.uk

One copy to be kept by the participant, one to be kept by the researcher

Participant Debrief

DEBRIEF STATEMENT

Flourishing Futures Autism Parenting Programme

Thank you very much for taking the time to participate in this study. The purpose of this study was to find if participating in the programme increased parents hope and well-being and decreased parents stress. A further aim was to find if participation led to decreased child anxiety and some behaviours that are associated with autism.

In the unlikely event that you feel affected by any aspect of this study or wish to talk to someone about any related issues, please contact the following:

The National Autistic Society: www.autism.org.uk

If you have any additional questions regarding this study, please contact either:

Researcher: Ruth Howard
Email: Ruth.Howard@bucks.ac.uk

Supervisor: Dr Piers Worth
Email: Piers.Worth@bucks.ac.uk
Department of Psychology
Buckinghamshire New University
Queen Alexandra Road
High Wycombe
Buckinghamshire HP11 2JZ
Tel.: 01494 522 141

Please keep this for future reference.

Appendix N

Risk Assessment

Risk Assessment: Sensory Overload Task

Identified Risks	**Likelihood**	**Potential Impact/Outcome**	**Risk Management/Mitigating Factors**
Identify the risks/hazards present	**High/Medium/Low**	**Who might be harmed and how?**	**Evaluate the risks and decide on the precautions**
Flashing lights	High	Participants who have seizure disorders may have a seizure induced. Participants with migraines associated with light and sound may have a migraine induced.	Researcher to explain the tasks to participants before commencing and enable people to refrain from participating. Researcher will explain that participants can stop at any time.
Metal scourers in cuffs of clothes	High	Participants may be allergic to metal or have existing skin conditions such as eczema or psoriasis irritated.	Researcher to explain the tasks to participants before commencing and enable people to refrain from participating. Researcher will explain that participants can stop at any time.
Loud music and sounds	High	Participants with migraines associated with light and sound may have a migraine induced.	Researcher to explain the tasks to participants before commencing and enable people to refrain from participating. Researcher will explain that participants can stop at any time.
Sensory overload of all senses	High	Participants may feel uncomfortable and this may induce stress.	The researcher will undertake a calming controlled breathing exercise with

			participants at the end of the task.
Standing on one leg	High	Participants may fall over.	The researcher will inform participants that if they feel imbalanced to the point they may fall they should stand on both legs.
Distress of participants	Medium	Participants may become distressed to experience an overload similar to their child's.	The researcher will undertake a calming controlled breathing exercise with participants at the end of the task, this will decrease distress and enable participants to learn how effective it can be for their children.

Appendix O

Focus Group Ethics and Documents

1.2 Co-applicants (please include everyone who will be involved in the research project, including research assistants)		
Name	Post held	Organisation
Dr Piers Worth	Reader	Bucks New University
Dr Matthew Smith	Senior Lecturer	Bucks New University
Professor Colin Martin	Professor	Bucks New University

Section 2: Project details

2.1 Project title and timescale	
Title	'Focus Group Consultation on Proposed Adapted Positive Psychotherapy Intervention for Autistic Young People and Their Families'
Proposed start date:	4th July 2016
Proposed end date: (of data collection)	31st September 2016

2.2 Costs and funding
Please indicate the total costs and source of funding (if applicable): Costs being met by the lead applicant.

2.3 Brief project description
This is the first of what will be two ethics submissions regarding the adaptation and development of a 'Positive Psychotherapy' intervention for use with autistic young people and their families. Positive Psychotherapy is a structured sequence of positive psychology exercises (between 8 and 15 depending on design) that have been found to enhance wellbeing and reduce symptoms in a number of different patient populations, such as mild to moderate depression, psychosis and schizophrenia (Bolier et al., 2013; Seligman, Rashid, & Parks, 2006; Riches, Schrank, Rashid, & Slade, 2015; Sin & Lyubomirsky, 2009). This process has been delivered mainly in group settings, but also one-to-one. The contribution of this process is still exploratory, and this application reflects a development of possible use.

Autistic people are found to have higher levels of mental health difficulties and co-morbid conditions than other populations (Dillenburger et al., 2015) and many of these are psychiatric in nature (e.g., Close, Lee, Kaufmann, & Zimmerman, 2012; Garcia-Villamisar & Rojahn, 2015).

The intention of this focus group study with parents of children and young people with autism, is to identify and explore what needs are being met currently, and what gaps there are in provision and support. Participants will be recruited through local and national charities that support the population. The findings will be used to inform the adaptation and development of a Positive Psychotherapy intervention in order to better meet the needs of this population.

Section 3: Research Design

3.1: Methodology/Methods

Please check boxes for all methodology/methods that you plan to use:

	Methodologies	
A	Case study	☐
B	Ethnography	☐
C	Life history/narrative	☐
D	Action research	☒
E	Participatory Research	☒
F	Dialogic enquiry	☐
G	Positivistic-Statistical	☐
H	Other methodology: Please give details	☐
	Methods	
A	Written questionnaires	☐
B	Semi-structured interviews	☐
C	Unstructured interviews	☐
D	Focus groups	☒
E	Observation	☐
F	Analysis of pre-existing data from human participants (where this data is sensitive or could be identifiable)	☐
G	Audio/video recording or photography in a public place	☐
H	Audio/video recording or photography in a private place	☐

I	Quantitative experiment	☐
J	Other method: please give details	☐

3.2 Research design

Describe and justify the methodology/methods you intend to use. Include details of and reasons for your sample selection and size to enable robust outcomes.

Parents views are to be consulted to develop the service which is informed by the needs of their children and families. This complies with the call from the autism community to be involved in the development of provisions as well as adhering to what is considered best practice in 'research for patient benefit' in gaining input from those affected by conditions. The lead applicant has significant experience of working with autistic children and adults and their families.

We aim to recruit three separate focus groups of 6-7 participants. The groups will comprise parents of children and young adults with autism in the following age ranges:

1. Primary school age (4 years to 11 years)
2. Secondary school ages (12 years to 18 years)
3. Young adults (18 to 25 years)

The focus groups are grouped in age as personal needs change with time and it is important that parents of younger children are not overwhelmed by the experiences of the older children and adults.

Grouping by age will also enable us to identify the needs of the differing age ranges, providing further information which can be utilised to adapt the intervention for age as well as autism. The group conversations will be recorded and transcribed. The groups will be held in the meeting room of a local charity in Leicestershire (Age UK, Earl Shilton) which is easily accessible, has large windows, negating the need for lighting, thus decreasing the potential for visual stress, and has good parking availability.

3.3 Ethical implications

Briefly outline any ethical implications of your research and how you propose to minimise these risks.

Parents of children and young people with autism have commonly experienced a range of complex difficulties, which may range from gaining a diagnosis for the condition, through to coping with the presentation of autism, and obtaining support for their needs.

Parents are being asked to give feedback on a possible research-based design of a programme that may support them and young people with autism. There is the likelihood that given their views are being sought on a positive development for change they will experience this opportunity as constructive and motivating.

Parents will be advised as part of the group process that they may withdraw without question. At the same time they will have been advised there may be limitations on how their 'data' can be extracted from a focus group process.

There is the potential that the discussion of these experiences may bring about stressful memories. The researcher is experienced in dealing with parents and young people with autism, in various contexts, including running support groups for parents, is alert to the kind of difficulties that may be disclosed, and will monitor the individuals within the group for their personal state. If any group member were to experience difficulties, we believe the environment will be supportive and there is a capacity to pause the focus group process while their needs can be attended to. There will be assistance from a second facilitator who has 6 years experience working with autistic young people in a specialist residential setting.

3.4 Dissemination

Please state how you intend to disseminate research findings. Include details of any Intellectual Property or security issues and whether dissemination is local or national.

The process of gaining input to design would be the basis of a journal article

Section 4: Participants and Recruitment

Section 4.1: Participants

Describe who you are looking to recruit into the project and why, including any criteria for inclusion / exclusion.

Parents of autistic children and adults whose children are aged 4 - 25 years.

The child must have received a formal diagnosis of an autism spectrum condition.

Section 4.2: Recruitment method

Provide a brief outline of how potential participants will be approached and recruited into the project (any recruitment materials should be included with the application). Please refer to the Bucks Guidelines for recruitment of participants for research.
http://bucks.ac.uk/research/research_ethics/research-ethics-guidance/

We have approached the Leicestershire Autistic Society to forward our recruitment emails to families on their mailing lists. The response was positive and they have agreed to support the recruitment of participants.

Information will be provided to respondents regarding the nature of the study, and will state that if respondents choose to continue they are providing informed consent.

Participants will be parents of autistic children and adults who will be recruited via a large local charity specialising in autism (Leicestershire Autistic Society). This charity has been chosen as it offers a range of projects and services which cover age ranges from early childhood to adults, thus enabling the recruitment of parents with a range of experiences and insights. Recruitment will be via email and request that potential participants apply to the research team via email.

Section 4.3: Vulnerability

If vulnerable people are allowed to take part in this study, give details and please indicate any necessary checks required by the researchers (eg Disclosure and Barring Service checks). Please refer to our Safeguarding Policy,

http://bucks.ac.uk/content/documents/Formal_Documents/Equality_and_Diversity/safeguarding-under-18s-and-adults-at-risk-policy-and-procedure)

The potential for parents to be in a 'vulnerable' state has been described in section 3.3 above and how this may be supported.

Section 4.4: Incentives

If your project will involve offering incentives of any kind, state what the incentives (financial or otherwise) will be and provide a brief justification as to why you feel this is necessary for the project.

Not applicable

Section 4.5: Gatekeepers / Permission

Please give details if permission is required for initial contact with participants or to access data (eg Headmaster, NHS R&D committee, Company manager, Head of School, HR). Include any documents for seeking permission or where permission has been granted.

The researcher works professionally with charities working with autism. We have approached a charity who responded positively and have agreed to support the recruitment of parents when ethical approval has been obtained.

Section 5: Consent procedure				
This section will demonstrate how you will obtain informed consent from the participants. *Please include all supporting documents (eg Information Sheets, Consent forms and questionnaires).* Please answer YES, NO or NOT APPLICABLE (N/A) to **each** of the following:				
		Yes	No	N/A
5.1	All respondents will be given an Information Sheet and enough time to read it before being asked to agree to participate.	☒	☐	☐
5.2	All participants taking part in an interview, focus group, observation (or other activity which is not questionnaire-based) will be asked to sign a consent form.	☒	☐	☐
5.3	All participants completing a questionnaire will be informed on the Information Sheet that returning the completed questionnaire implies consent to participate.	☐	☐	☒
5.4	All participants being asked to provide sensitive personal data will have the following statement on the consent form or on the bottom of their questionnaire "I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the UK Data Protection Act 1998''. A tick box should be included to allow participants to give explicit consent for the collection and use of such data.	☒	☐	☐
5.5	All respondents will be told that they can withdraw at any time, ask for their interview tape to be destroyed and/or their data removed from the project until it is no longer practical to do so (e.g. when the report has been written up).	☒	☐	☐
5.6	Where full information cannot be given prior to participation (because it could influence outcomes) participants will be fully de-briefed after participation.	☐	☐	☒
5.7	If you answered NO to any of the above (or think more information could be useful to the reviewer) please state why here:			

Section 6: Confidentiality, Anonymity & Data and Records Management				
This section will show how participants can expect confidentiality and/or anonymity and will show how any research data collected will be managed during and after the study. *Confidential data is not disclosed to other people; Anonymous data cannot be linked to the participant's personal details.* Please answer YES, NO or NOT APPLICABLE (N/A) to each of the following:				
		Yes	No	N/A
6.1	Questionnaires will be returned anonymously and indirectly. Please note that questionnaire data cannot then be followed up/clarified.	☐	☐	☒

6.2	Questionnaires and/or interview transcripts will only be identifiable by a unique identifier (e.g. code/pseudonym)	☒	☐	☐
6.3	Lists of identity number or pseudonyms linked to names and/or addresses will be stored securely and separately from research data	☐	☐	☒
6.4	All place names and institutions which could lead to the identification of individuals or organisations will be changed	☐	☐	☒
6.5	I confirm that all processing of personal information related to the study will be in full compliance with the UK Data Protection Act 1998 (DPA) (*including the Data Protection Principles)*	☒	☐	☐
6.6	I confirm that processing of all security sensitive information will be in full compliance with the "Oversight of security - sensitive research material in UK universities: guidance (October 2012)" (Universities UK, recommended by the Association of Chief Police Officers)	☒	☐	☐
6.7	If you answered NO to any of the above (or think more information could be useful to the reviewer) please state why here:			

Section 7: Authorisation

For employees:

Please ask your Head of School to sign that they have read the application form and that they accept responsibility for the applicant who is undertaking the work in their School.

Signed: …….

Head of School

Date …….

For postgraduate researchers, postgraduate taught students and undergraduate students:

Please ask your supervisor to sign that they have read the application form and that they accept responsibility for the applicant who is undertaking the work.

Signed ……

Supervisor

I, as the Supervisor, recognise the benefit of attending the ethics committee meeting with the student

Signed …….

Supervisor

Date …….

Section 8: Checklist for Applicant
☒ The Ethics application form ☒ The Participant Information Sheet ☐ The Consent Form ☐ Letters seeking/granting permission for access to data/participants ☐ Materials for recruitment of participants ☐ Questionnaire ☐ Interview schedule ☐ Authorisation received

Recruitment Email Content

We are passionate about supporting autistic people to reach their potential and to live fulfilled and flourishing lives.

We are planning to develop a programme to help increase the wellbeing of autistic children and young adults to enhance and support people to reach their potential.

In order to achieve this, we are conducting research into the experiences of autistic children and adults regarding their wellbeing. This is to ensure that the intervention programme takes into account the views and needs of the population and their families.

We would like to invite parents to participate in a focus group to comment on and contribute to the design of this programme. We will not ask any personal information or collect any data that would identify a person.

To participate in the research, please email the research team using the address below.

We thank you for your time and contribution.

Ruth.Howard@bucks.ac.uk

Participant Information Sheet

'Focus Group: Feedback on a Proposed Intervention to Enhance the Wellbeing of Autistic Young People.'

We are asking parents of autistic adults and children about their child's current and previous well-being. We are also asking parents their views on possible future interventions and support. This is to ensure that our understanding of people's needs and subsequent programmes that we develop are informed by families themselves.

We will be conducting three focus groups for parents of young people with autism in specific age ranges. We anticipate these will take approximately 90 minutes. This will involve you being asked questions and to comment on the design of a possible programme with particular focus on whether and how you believe it may contribute to the experiences of young people with autism.

Your participation is entirely voluntary and you may choose to discontinue your participation at any time during the focus group. However given this will involve a group discussion, removing your views from the research would not be practical.

All information collected will be used for research purposes. By participating you are contributing to the growing body of research highlighting the needs of autistic people and their families.

The risks of participating with this study are perceived to be minimal, a few people may find that questions cause distress. Every care will be taken during the focus group for this discussion to be supportive.

CONSENT FORM

Focus Group: Feedback on a Proposed Intervention to Enhance the Wellbeing of Autistic Young People.'

Please tick the following

I have read and understood the project information sheet..…..…… ☐

I have been given the opportunity to ask questions about the project…… ☐

I agree to take part in the project. Taking part in the project will include participating in a group discussion regarding a proposed project which intends to train parents, to undertake positive psychology exercises at home with their autistic child and wider family. Feedback will be sought regarding the general applicability of the programme, the exercises and adaptations and additions that could be made. ☐

I understand that my taking part is voluntary; I can withdraw from the study at any time and I will not be asked questions about why I no longer want to take part…….. ☐

I understand my personal details such as phone number or address will not be revealed to people outside of this project……. ☐

I understand that my words may be quoted in publications, reports, web pages, and other research outputs but my name will not be ☐

I understand that other researchers will have access to these data only if they agree to preserve the confidentiality of these data…… ☐

I understand that other researchers may use my words in publications, reports, web pages and other research outputs…… ☐

On this basis I am happy to participate in the Focus Group: Feedback on a Proposed Intervention to Enhance the Wellbeing of Autistic Young People.'study

Name of Participant …… Signature……Date…….

Name of Researcher Ruth Howard Signature……Date…….

If you have any queries or concerns, please contact Ruth Howard ruth.howard@bucks.ac.uk; Piers Worth Piers.Worth@bucks.ac.uk; Matthew Smith Matthew.Smith@bucks.ac.uk**One copy to be kept by the participant, one to be kept by the researcher**

Anticipated focus group process and content:

Participant Introduction

Welcome.

Safety, fire exits, toilets, refreshments.

Thank you for taking the time to participate in this exciting research project.

We would like to briefly describe our research and aims of the focus group today.

Research
We are looking to develop a programme that will teach parents how to use positive psychology with their children. Positive psychology is relatively a new area of psychology that has been shown to help benefit wellbeing.

Our review of the literature regarding autism shows that autistic children and adults tend to have higher levels of anxiety and mental health problems than other groups. We have also found that the development of life skills is often delayed.

We are not aware of any current programmes that help parents to enhance their children's wellbeing and life skills and aim to adapt an existing intervention and include life skill development activities within the programme.

Today, we will provide you with an overview of our planned programme and would like you to provide us with feedback. The feedback we are looking for is the general suitability, needs of your children and family in relation to the proposed programme, ideas to further adapt the programme, ideas for removal, changes and inclusions. This is not an exhaustive list and welcome and ideas and feedback that you may have!

Process
We will achieve this using the following steps:

1. Overview – we will explain the programme and content using PowerPoint and you will be given handouts.

2. Split into two groups and discuss your ideas and thoughts. Please write down your suggestions and ideas for changes, inclusions. We would like you to consider the following:

    - General suitability of the exercises to your child and family
    - The needs of your child and family in relation to the proposed programme – do you think that it will help?
    - Ideas to further adapt the programme. Is there anything missing?
    - Ideas for removal. Are there exercises that you think are inappropriate? If so, in what way?
    - Any other changes?

- Anything missing? What else should we include?

This is expected to take approximately an hour, though may take longer.

3. Whole group feedback of ideas which will be recorded on a flip chart.
4. Group discussion. This will be recorded on flip chart.

The two researchers will take notes during the process, these notes will be identifying the type of discussion, feedback and comments being made. This is to ensure that we are generating a deeper insight into the needs of the community and will enable us to gather richer and meaningful information. The discussions will also be recorded and transcribed.
Refreshments are available, please feel free to help yourself.
If you require any assistance or have any problems, please don't hesitate to ask.
Thank you

De-brief

Thank you for taking the time to participate in this focus group, we greatly appreciate it.

We are planning to develop a programme to help to enhance the well-being of autistic children and adults and their families. Our aim is to decrease mental ill health and increase the opportunity for individuals to reach their potential. Our review of the literature and previous research has found that autistic children and adults tend to have higher levels of anxiety and depression than other populations. We have also found that the wider family are also affected by high levels of stress.

Positive Psychology is interested in human flourishing and interventions have proven to be effective in helping people with various difficulties such as depression and psychosis. Our intended programme will adapt these interventions to make them autism friendly and train parents how to use them in daily life. We believe that this will help to decrease mental ill health and increase opportunities for success.

In order to achieve our aims, it is essential that we take the views and experiences of the autistic community into account and use these to ensure that the programme meets the needs of the community. We are grateful for your participation in this study and should you require further information please contact the lead researcher via the email address below.

If you should experience any distress as a result of participating in this study, or wish for support as a result of it you may contact:

Your GP
The National Autistic Society: 0808 800 4104
The National Autistic Society Parent to Parent Helpline: 0808 800 4106
Young Minds: 0808 802 5544
Scope: 0808 800 3333
The Samaritans: 116 123
Lead Researcher: Ruth Howard Ruth.Howard@bucks.ac.uk
Project Supervisor: Dr Piers Worth Piers.Worth@bucks.ac.uk