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A Life Lived in the Shadows: Social and Emotional Functioning in Older Autistic Adults and the Potential for Successful Ageing

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Abstract

Ageing in autism spectrum conditions is a growing but still relatively under-researched field of enquiry. Changes in the diagnostic features, particularly social and communication difficulties, and emotional and mental health needs of autistic adults as they age is one area that is not well understood. This thesis presents a program of work encompassing both empirical and theoretical research. Firstly, it used an exploratory qualitative methodology to investigate the social and emotional functioning of cognitively able older autistic adults. Secondly, using theoretical analysis it outlines and provides empirical evidence for the application of the theory of lifespan psychology to the developmental trajectory of autism across the lifespan. The aim of this research was twofold: to explore older autistic adults' experiences and perspectives of ageing, with particular focus on social-emotional functioning; and to investigate the relevance of lifespan developmental psychology as a theoretical framework for understanding adaptive change and the potential for successful ageing in autism.

The first part of this research program used Interpretative Phenomenological Analysis, a psychological experiential methodology, that lends itself to participatory research and is well-suited to generating theory, particularly in under-researched areas such as ageing in autism. Semi-structured interviews with ten autistic adults (age range 53-74 years) explored their life history and experiences of autistic identity, social interaction, mental health and coping, and concerns for the future. Analyses revealed four overarching themes: negotiating diagnosis and an autistic identity in later life; social instinct; mental health problems and solutions; and positive outlook. Participants' insights highlighted that respect for, and accommodation of, diverse experiences is critical in autism research, and in treatment and support contexts. Further, despite experiencing many life difficulties, participants suggested older age brought with it resilience and a generally positive outlook on life. This finding contrasts with other studies of autistic adults that report a steady and unchanging life trajectory of isolation, loneliness and longing for connection, and suggests that older autistic adults with low support needs might attain normative developmental gains in later life despite their autistic characteristics.

Negative misconceptions about the inevitability of decline and loss in old age abound in society and the literature on autism and ageing. But there is a paradox of ageing – most typically developing adults experience a peak in their life satisfaction and emotional wellbeing in later life that is fundamental to successful ageing. The resilience and positive outlook of older autistic adults revealed in the first part of this research program was an unexpected finding, and raised the tantalising question: could it be that the paradox of ageing is true for older autistic adults too?

Although autism has been analysed in the context of many theoretical frameworks, most take as their starting point impairment and disability even as they advocate for a positive neurodiverse conceptualisation of autism. By contrast, there has been no attempt to consider ageing in autism from the perspective of lifespan psychology and developmental models that guide much of the contemporary gerontological research on social and emotional development and successful ageing. The second part of this research addressed this gap in the literature by exploring how lifespan psychology, and the developmental model of selective optimisation with compensation, might inform our understanding of the developmental trajectory of autism across the lifespan and in later life. Drawing on evidence from the autism literature and the case studies of three older autistic adults in the current program of research, it is contended that lifespan psychology provides a novel conceptualisation of successful ageing in autism as the outcome of lifelong adaptive processes in the pursuit of personal meaning and goals.

The program of research described here adds to our knowledge of autism and ageing by providing unique and nuanced insights into social and emotional functioning across the lifespan from the perspectives of older autistic adults. Further, it proposes lifespan developmental psychology as a novel evidence-based theoretical framework that challenges existing negative expectations and offers an opportunity to reframe future autism research and clinical practice. Overall, this body of work extends our understanding of ageing in autism and offers a fresh and creative direction for future research that focuses on the potential for growth, wellbeing, and successful ageing in autism. Limitations of the research and areas for future research are also discussed.

Declaration by author

This thesis *is composed of my original work, and contains* no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

I have clearly stated the contribution of others to my thesis as a whole, including statistical assistance, survey design, data analysis, significant technical procedures, professional editorial advice, financial support and any other original research work used or reported in my thesis. The content of my thesis is the result of work I have carried out since the commencement of my higher degree by research candidature and does not include a substantial part of work that has been submitted *to qualify for the award of any* other degree or diploma in any university or other tertiary institution. I have clearly stated which parts of my thesis, if any, have been submitted to qualify for another award.

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Publications included in this thesis

No publications included.

Submitted manuscripts included in this thesis

No manuscripts submitted for publication.

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Contributions by others to the thesis

This project was designed in consultation with my advisory team, Associate Professor Kate Sofronoff, Professor Tony Attwood and Professor Nancy Pachana.

Professor Tony Attwood assisted with initial introductions to some participants to facilitate gathering information and the pilot data that informed the specific areas of investigation of the project.

Associate Professor Kate Sofronoff conducted the clinical assessments of participants who wished to clarify their diagnostic status.

I attended a workshop to learn about qualitative methodology, but all analyses were conducted by me. An autistic research assistant conducted a credibility check of the data analyses in accordance with the methodology used and the participatory approach of this program of study.

The advisory team read drafts of all the chapters of this thesis and provided feedback but did not contribute to or alter interpretation of the research data.

Statement of parts of the thesis submitted to qualify for the award of another degree

No works submitted towards another degree have been included in this thesis.

Research Involving Human or Animal Subjects

This study was cleared in accordance with the ethical review processes of the University of Queensland and within the guidelines of Australia's National Statement on Ethical Conduct in Human Research. The Ethics approval number is 16-PSYCH-PHD-29-JS. See Appendix A. for a copy of the ethics approval letter.

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Keywords

autism, successful ageing, social functioning, emotion regulation, outcomes, positivity, wellbeing, resilience, compensation, developmental trajectory

Australian and New Zealand Standard Research Classifications (ANZSRC)

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Dedications

To my family for their support and patience, especially the latter.

To my mother, for her support and encouragement and, most importantly, for being a constant inspiration: the embodiment of healthy, successful – and joyful – ageing to which I aspire.

To the autism community who assisted with my research, especially the participants who shared their life stories so trustingly and with such good humour. Your courage and resilience gives hope for the future.

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Abbreviations

ALSAA	Australian Longitudinal Study of Adults with Autism
APA	American Psychiatric Association
AS	Asperger's syndrome
ASC	Autism Spectrum Condition
ASD	Autism Spectrum Disorder
ASQoL	Autism Spectrum Quality of Life measure
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition – Text Revised
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, Third Edition
EMA	Ecological momentary assessment
IPA	Interpretative Phenomenological Analysis
IQ	Intelligence Quotient
PROMIS-10	Patient-Reported Outcomes Measurement Information System Global-10
QoL	Quality of Life
RRB	Restricted Interests and Repetitive Behaviour (SRS-2)
SCI	Social Communication Index (SRS-2)
SOC	Selective Optimisation with Compensation
SRS-2	Social Responsiveness Scale, Second Edition; Adult Self-Report version
SST	Socioemotional Selectivity Theory
ToM	Theory of Mind
WHO	World Health Organization
WHOQOL-Bref	World Health Organization Quality of Life Instruments

PART I: THE PAST

Chapter 1: Thesis Overview

"It's been a bit of a muddled life, really" **– Anne, 69 years**

Ageing in autism is a startlingly under-represented field of study within the broader field of autism research. The importance of systematically investigating the lifetime course of autism was strongly emphasised decades ago by the pioneers of autism research, Leo Kanner (Kanner et al. 1972) and Hans Asperger (1991). However, research agendas in the intervening years have narrowed their focus almost exclusively to autism spectrum conditions in children and, to a lesser extent, to adolescent and younger adult populations. Although this imbalance is slowly changing, it is still the case that very little is known about the developmental trajectory of autism spectrum conditions beyond early adulthood and into old age. There is a myriad of aspects of ageing on the autism spectrum requiring investigation, but as autism is a developmental condition, a priority is the need to identify what, if any, changes occur in autism symptomology and the social and emotional functioning of autistic adults as they age, and what implications arise from these changes. Therefore, there were two aims of this program of research. The first aim was to contribute to bridging the gap in our understanding of the developmental trajectory of autism by using a qualitative methodology to explore cognitively able older autistic adults' experiences, perspectives, and insights on changes in their autistic characteristics and social and emotional functioning across the lifespan through one-on-one semi-structured interviews. Because there is still so much that is not known about this stage of life in autism, rather than formulate and test hypotheses, the purpose of this part of the research program was explorative: to identify themes and patterns in experience that might inform our understanding and suggest directions for future research. The second part of the research program was to look beyond autism research to the broader field of developmental lifespan psychology in an attempt to understand if and how the theoretical propositions that have guided much of the research on social and emotional ageing in typically developing adults might be relevant to and provide context for our understanding of autism and ageing.

This thesis is presented in three parts. The first part comprises two narrative literature reviews to provide context to the following chapters. Chapter 2 is a review of the autism literature on social functioning and its various components. It also overviews what is known about other aspects of social functioning in autism in relation to context and environment, social strategies used by autistic adults, quality of life and lived experience. What is known about aspects of social functioning in older autistic adults is also reviewed. In Chapter 3, the second narrative literature review explores the literature on successful ageing, particularly in the social and emotional domains, in the typically developing population. This leads to an overview of outcomes in autism and the factors that might impact on successful ageing in autism spectrum conditions. It is important to note that as autism and ageing research is still very much at a pre-paradigmatic stage, studies vary widely in terms of methodology and topic category. Further, identifying literature on autism in later life is difficult because there is not consistency in keywords or search terms. For these reasons it was deemed that narrative literature reviews rather than a systematic review more appropriately served the research purposes of this thesis. Chapter 4 presents the methodology used to analyse interview data in this research program. The theoretical and practical aspects of Interpretative Phenomenological Analysis (IPA) are reviewed, and the analytical process undertaken in this body of work is explained.

Part two of the thesis comprises Chapters 5 to 8 which report on the four themes, and their respective underlying sub-themes, identified in the analyses of participants' interview data. Qualitative data cannot be easily summarised in tables of numerical data and to do so is inconsistent with IPA methodology. To accommodate the wealth of detailed data generated by the analyses in this research each theme is presented as a stand-alone chapter. As such, Chapter 5 explores participants' experiences of negotiating and accepting an autism diagnosis; Chapter 6 reveals sub-themes relating to social instinct in autism; Chapter 7 explores experiences and perspectives on emotion regulation; and Chapter 8 presents the theme of poignancy and positivity. Each chapter presents the data and interpretation of each theme and its sub-themes and concludes with a discussion and summary of conclusions.

Finally, in part three of this thesis, Chapter 9 proposes lifespan developmental psychology as a theoretical framework for understanding and promoting successful ageing in autism. This proposition is examined and supported by theoretical analysis and empirical evidence from autism research. Chapter 10 follows with three cases studies analysed in the context of selective optimisation with compensation (SOC), a developmental lifespan model of successful ageing. Part three concludes with Chapter 11 which discusses limitations of this research program, theoretical conclusions, and suggestions for future research.

1.1 Terminology

1.1.1 Autism

This thesis uses the terms autism and autism spectrum condition (ASC) and their derivatives interchangeably rather than the DSM-5 diagnostic term, Autism Spectrum Disorder (ASD), to reflect the preferences of individuals who regard the autism spectrum as a range of different abilities rather than a disability or disorder. Similarly, person-first (e.g., 'older adult with autism') and disability-first (e.g., 'autistic older adult') terms are also used interchangeably to reflect the diversity in identity preference amongst people in the autism community, particularly in an Australian context (see Bury et al., 2020), and in this research program. Asperger's disorder is termed Asperger's syndrome and abbreviated to AS.

1.1.2 Old Age

The concept and definition of old age varies, even amongst ageing researchers. In geropsychology, age stratification is typically understood according to chronological age, with "young old" referring to those aged approximately 65 to 74; "middle old" to those aged approximately 75 to 84 years; and "old old" referring to individuals aged over 85 years (Notthoff & Gerstorf, 2017). However, in autism research, 50 years and over is regarded as an appropriate age threshold for "old" or "older" autistic adults to take account of the potential influences of the complex health problems and lower life expectancy associated with autism (Roestorf et al., 2019). As such, all participants in the study conducted as part of this research program were aged 50 years or older and therefore deemed "older autistic adults". According to normative ageing classifications participants in this study aged 50 to 64 years are "middle-aged" and those aged 65 years and over are "young old".

Chapter 2: Social Functioning in Autism Spectrum Conditions — A Narrative Literature Review

Difficulty relating to other people in the "ordinary way" was at the core of Leo Kanner's (1943) seminal paper describing autism and refers to the social difficulties – impaired social instinct and problems with social communication and imagination – that have a profound impact on the lives of people on the autism spectrum (Wing, 2005). Similarly, Hans Asperger identified in the first paragraph of his landmark paper on 'autistic psychopathy' in childhood that the condition was characterised by "severe difficulties of social integration … so profound that they overshadow everything else" (Asperger, 1991; p. 37). These difficulties manifest as problems with social-emotional reciprocity, non-verbal communication, including using and understanding body language and facial expressions, forming and maintaining relationships, and adapting behaviour in response to varying social contexts (American Psychiatric Association, 2013). Impairments in social communication and interaction remain central to the diagnostic criteria of autistic spectrum disorder (American Psychiatric Association, 2013) despite revisions over the decades as diagnostic categories and labels have been amended and updated from DSM-III to DSM-5 to accommodate developments in clinical and community views about the nature of autism (Rosen et al., 2021). Diagnostic descriptions have evolved and expanded from extreme social aloneness in children as a feature of infantile autism in DSM-III to impaired social instinct in either children or adults in Asperger's Disorder in DSM-IV and, most recently, to acknowledgement in DSM-5 that socio-communicative difficulties may not be observable until "social demands exceed limited capacities, or may be masked by learned strategies in later life". (American Psychiatric Association, 2013, p. 50; Lai & Baron-Cohen, 2015). This most recent expansion acknowledges that diagnostic criteria must accommodate the many autistic adults still undiagnosed in later life (Brugha et al., 2011). For some their autistic symptoms cause clinically significant impairment in social functioning (Lord et al., 2018) meaning that at some point in later life social difficulties become so challenging that everyday functioning is impaired (Happé & Frith, 2020; Howlin, 2021). However, there is still much that is not known about the developmental trajectory of social functioning in autism across the lifespan, and particularly how it manifests in old age.

Perhaps the first investigation of the trajectory of social functioning in adults with autism was Kanner's follow-up study of eleven of his original child patients when they were in their 20s and 30s (Kanner et al., 1972). Kanner was interested in identifying the factors that contributed to them being "sufficiently integrated into the texture of society" (p. 10) to such an extent that they could live relatively full lives, perhaps somewhat like a precursor to the "lost generation" of undiagnosed older adults in today's society (Lai & Baron-Cohen, 2015). Kanner identified social motivation as one such factor, and he observed this as a characteristic that this sub-group of young and middle-aged adults had developed from their teenage years when they first became socially – or "uneasily" (p. 29) – aware of being different from their peers. According to Kanner, it was at this life stage that self-awareness triggered a desire to adapt to the social environment around them, most often by making a conscious effort to harness their individual talents and special interests, once deemed isolating but now put to positive effect. These talents and special interests were used to compensate for perceived social difficulties and make connections with others around them, pursue education and find employment.

However, 50 years later and despite its centrality to autism, much about the social and communication abilities that might have aided or undermined social functioning in late-diagnosed highly able individuals across the lifespan, and the individual characteristics that might have contributed to relatively successful functioning, is still open to debate (Happé & Frith, 2020). Indeed, there is not an agreed operational definition for social functioning (Uljarević et al., 2020). Instead, a range of subdimensions of social communication deficits in autism that may contribute in varying ways and at different stages of development have been investigated to determine how or whether they occur in patterns, which in turn might lead to a more consistent conceptualisation of social functioning problems, possible phenotypes, and a better understanding of their cascading or downstream effects throughout development (Happé, 2015; Rosen et al., 2021; Kang et al., 2020; Zheng et al., 2021).

For now, social functioning is most commonly conceptualised as a complex combination of social motivation, social skills and social anxiety, with varying levels of ability across these behavioural components determining autistic individuals' ability to navigate social interactions and relationships (Pallathra et al., 2018). Associated elements of the socio-communication domain that have also received significant research attention are socio-cognitive (e.g., Theory of Mind (ToM) and mentalising) and socio-affective processes (e.g., empathy and alexithymia). Both social cognition and social affect are considered essential to higher-level (flexible; multifaceted) social processing and interaction because they facilitate access to others' inner thoughts, feelings and motivations (Happé et al., 2017; Kanske, 2018; Preckel et al., 2018).

This chapter will review what is known about these components of social functioning and other contributing factors associated with autism. Because there is relatively little known about social functioning in older autistic adults most of the literature reviewed relates to autistic adults. As such, Section 2.1 addresses the components of social functioning and is followed by a deeper exploration of social cognition and social affect in Sections 2.2 and 2.3 respectively. Context and environment and social strategies are also important factors associated with autistic social functioning and are reviewed in Sections 2.4 and 2.5 followed by a review of the influence of social functioning on quality of life. Importantly, these sections provide background and context to the final sections of the chapter (2.7 and 2.8) which outline the little that *is* known about older autistic adults' social functioning and their personal experiences and perspectives. Drawing on the gaps and limitations identified in the literature reviewed, the chapter concludes with the associated rationale and aim of this thesis' program of research.

2.1 Components of Social Functioning

2.1.1 Social Motivation

Kanner et al. (1972) noted that social awareness was a driver of social motivation in autistic adults, and more recently research – and debate – has focused on social motivation, or the lack thereof, in autistic adults. Behaviourally, social motivation is a combination of social orienting and attention, seeking and liking social situations and interactions, and consciously striving to maintain a positive social image and reputation (Chevallier et al., 2012). Social motivation drives the establishment and maintenance of social bonds and relationships and facilitates cooperation and collaboration with others and it may be an important moderating factor in the loneliness of autistic adults, and the development of mental health issues such as depression (Smith & White, 2020).

However, there are different stances on the inherent social motivation of people on the spectrum (Chevallier et al., 2012; Livingston et al., 2019). According to Chevallier et al. (2012), lower levels of social motivation and associated reduced interest in social interaction means autistic individuals do not feel loneliness or experience it in the same way as neurotypical adults. An alternative proposition is that social motivation – like much else in autism – may vary at an individual level and across the lifespan (Livingston et al., 2019; Smith & White, 2020). While some autistic individuals with atypical levels of social motivation persist with social interaction despite negative side-effects such as exhaustion and mental health problems, others who are less socially motivated may have a lower threshold for tolerating social cognitive difficulties and compensatory strategies (Livingston et al., 2019b). For autistic adults who are highly socially motivated but may have poor socio-communication skills or self-regulation, repeated social failure can leave them vulnerable, and lead to poor self-esteem, social isolation, and mental health problems (Lai & Baron-Cohen, 2015; Uljarević et al., 2020). For some who have social difficulties coupled with an absence of social motivation there is little difference between their desire to connect socially and their ability to successfully negotiate interpersonal relationships, and so they are less at risk of loneliness and flow-on mental health problems. But for others who are highly socially motivated but have poor social communication skills that lead to relationship breakdowns there is a cognitive dissonance that leads to hurt and confusion and a determination to never again attempt to form a close relationship (Brugha, 2018).

2.1.2 Social Anxiety

Lifetime prevalence of anxiety in autism is high, but at 20 per cent it is particularly so for social anxiety (Hollocks et al., 2019). This may be partially due to greater social vulnerability, as a result of social and communication difficulties, to aversive life experiences (Griffiths et al., 2019) such as social exclusion and bullying (Happé & Frith, 2020). A discrepancy between an individual's desire to engage socially, and their difficulty in doing so can also cause psychological distress for some (Kang et al., 2020). Awareness of social difficulties and fear of negative evaluation by others is also thought to contribute to anxiety in adults with ASC (Maddox & White, 2015). For instance, some adults who have difficulty interpreting the context in social situations worry about responding inappropriately (Spain et al., 2020), which leads to anxiety. Many autistic adults have insight into their core social problems and difficulties, which magnifies a fear of negative evaluation in social settings, exacerbates their anxiety, and in turn undermines confidence in accurately reading social cues and results in social awkwardness (Maddox & White, 2015). For many, social avoidance, an overlapping symptom of both ASC social impairment and anxiety (Cai et al., 2018), becomes a coping strategy and completes a vicious cycle in which negative experiences lead to social withdrawal and therefore fewer social opportunities to develop and practice already impaired social skills (Maddox & White, 2015). Other compensatory social coping strategies used to assimilate in social settings, such as camouflaging and masking autistic behaviours, also contribute to social anxiety (Hull et al., 2021).

Specific research on anxiety disorders such as social anxiety in older adults is scarce (Wise, 2019). However, in an investigation of trends in self-reported anxiety in adults across the lifespan, Uljarević and colleagues (2019) found a slight increase in adolescence through to middle-age, but then a decline in older adulthood. This trend has been identified in other studies investigating social anxiety in older adults (Lever & Geurts, 2016b) and social cognition across the lifespan (Pagni et al., 2020) and it has been suggested that perhaps older age brings with it learned coping strategies and social skills and greater self-acceptance that help reduce feelings of anxiety and stress in social situations. It is currently unknown whether this trend exists for older adults on the autism spectrum.

2.1.3 Socio-Cognitive and Socio-Affective Processes

Historically, autism research has explored cognitive theories to identify the pathways between heterogeneous biological and behavioural features of autism that lead to difficulties with social interaction and impaired social functioning (Fletcher-Watson & Happé, 2019). "Social cognition", a complex interweaving of behavioural, neural and emotional processes (Happé et al., 2017) is vital to social interaction and not surprisingly has a positive association with social functioning in autistic people (Bishop-Fitzpatrick, Mazefsky et al, 2017), which may explain why it has historically been a primary focus of autism research. Emotion regulation and social cognition are inextricably related; they share processing strategies that are important to both social and emotional functioning (Adolphs, 1999), and the ability to accurately assess others' mental and emotional states is crucial for adaptive responses in any given social environment (Norris & Cacioppo, 2007). In autism literature social cognition is typically conceptualised as encompassing affective or emotional information processes such as emotion recognition, empathy – and its "opposite", alexithymia – as well as more obvious cognitive processes such as language, memory, social attention and learning, executive functioning, and theory of mind (ToM; Happé et al., 2017). It is thought that these components of social cognition are likely inextricably but differentially related throughout developmental stages, and delays or deficits in some, at critical developmental periods, may have lifelong consequences for abilities in others (Happé et al., 2017). In the past decade and a half there has been a significant increase in research focus on empathy in autism. People with autism are capable of demonstrating typical emotional awareness, emotion recognition, eye-contact and empathy (Brewer et al., 2015), and while there is wide variation in their ability to read facial expressions, autistic individuals' ability to integrate emotion cues from both faces and bodies is similar to that of typically developing people (Brewer et al., 2017).

Other fields of psychology differentiate between socio-cognitive (e.g., ToM) and socio-affective (e.g., empathy) processes as separable albeit jointly necessary for flexible and responsive social interaction and decision-making (Preckel et al., 2018), and it is now understood that ToM and empathy, while often engaged simultaneously, are nonetheless two completely dissociated elements of social cognition served by distinctly different neural networks (Bird et al., 2010; Preckel et al., 2018). It is known that ageing in typically developing adults has a differential effect on both (Reiter et al., 2017). Thus, socio-cognitive and socio-affective functions in autistic adults and ageing will be addressed separately, albeit briefly.

2.2 Social Cognition

Social cognition is important for understanding the perspective of others, their actions and interactions, and impairment in this domain is strongly associated with social functioning difficulties in autism (Bishop-Fitzpatrick, Mazefsky et al., 2017; Happé, et al., 2017; Leekam, 2016; Yarar et al., 2020). However, much about the structure and processes of social cognition is not fully understood. In a detailed overview of the research literature on social cognition, Happé and colleagues (2017) identified inter-related social abilities that are key to social cognition, including social learning, motivation and attention, as well as theory of mind, emotion recognition and empathy. The authors emphasised the importance of distinguishing between social ability, typically gained through learning from others and trial-and-error, and propensity to engage in social situations. They postulated that social abilities might be achieved through two routes of social processing: a fast, automatic and heuristic process that reflects propensity in social interactions; and a slow, deliberative and more rational approach that reflects the accuracy of social reasoning. How the components of social cognition are interrelated is unclear (Morrison et al., 2019) and evidence for changes in social cognition over the lifespan is inconsistent.

2.2.1 Theory of Mind

In its most simple and universal everyday form, ToM is the ability to infer and reason about one's own mental state as well as the beliefs and thoughts of others. This ability to follow what others are thinking is a vital social skill (Happé, 2015), and impaired social functioning may be the result of specific theory of mind deficits (Bishop-Fitzpatrick, Mazefsky et al., 2017), which have downstream consequences for being able to appropriately adapt emotional processes (such as facial expressions and empathy) to social contexts (Brewer et al., 2015; Norris & Cacioppo, 2007). Many adults have the ability to pass explicit ToM tests (for example, in lab-testing situations) but that ability may not generalise to the complexity of real-life situations (Happé et al., 2017). That is, there is ToM ability, but a reduced propensity to use it. It is not known if acquired albeit delayed ToM ability is the result of autistic individuals "catching-up" developmentally, learned compensatory strategies, or having sufficient intellectual ability to accommodate the extra cognitive processing necessary to pass (Fletcher-Watson & Happé, 2019). Certainly, cognitive ability and verbal IQ are strongly associated with performance on higher order mentalising tasks, suggesting that autistic individuals with more cognitive resources have a compensatory advantage (Morrison et al., 2019).

2.3 Social Affect

The ability to express and perceive emotions is integral to social interaction (Decety, 2007). Humans are intrinsically social beings and almost all of a person's feelings and thoughts are targeted at or are a response to someone else, meaning that the ability to understand and share the feelings of someone else is in itself inherently social (Decety, 2007). Components of social affect have historically been incorporated into autism research as socio-cognitive processes (Fletcher-Watson & Bird, 2019; Happé et al., 2017). Because empathy, and alexithymia in particular, have been poorly defined and operationalised in studies (Fletcher-Watson & Bird; 2019; Kinnaird et al., 2019), research findings may not reflect real-life abilities and performance in social interactions (Morrison, DeBrabander, Jones, Ackerman, et al., 2020). Indeed, emerging evidence suggests that, like typically developing people, autistic individuals are able to integrate emotional facial and body cues (Brewer et al, 2017), serving to debunk "traditional" characterisations of autistic impairment such as inability to read facial cues and further supporting the role of alexithymia rather than autism in socio-affective impairments (Bird & Cook, 2013).

2.3.1 Empathy

Empathy describes the affective response in which one person takes the perspective of another, and experiences or shares in their emotions or feelings which is so crucial to social interaction (Decety, 2007). Sometimes referred to as emotion sensitivity (Garfinkel et al., 2016) or affective or emotional empathy (Harmsen, 2019) it is the basis for prosocial and altruistic behaviours such as compassion (Preckel et al., 2018) and evidence for this more positive aspect of autism is growing (McConachie et al., 2020). It is broadly understood as a series of steps: the ability to notice, interpret and resonate with another person's feelings or emotions and then to respond to it in a socially expected way (Fletcher-Watson & Bird, 2019). While each step might be difficult for an autistic individual, it is the final step that may prove particularly challenging as it engages social attentional processes that are inherently difficult for someone with socio-communication impairments. Empathy is often conflated with ToM in autism research (Fletcher-Watson & Bird; 2019) however, while for some autistic individuals difficulties with ToM means that inferring and reasoning about what another person is thinking is effortful or impaired, this does not mean they cannot feel or care for others (Fletcher-Watson & Happé, 2019) and indeed for many autistic people emotions can be intensely experienced (Mazefsky et al., 2013) This readjustment away from a conceptualisation of autistic people as unfeeling or lacking in empathy is long overdue and is consistent with some of the first psychological observations of autism (at the time called "schizoid", and later re-labelled "autistic", psychopathy) by Grunya Sukhareva, a Russian child psychiatrist, in the mid-1920s (Manouilenko & Bejerot, 2015; Wolff, 1996, 2004). In a case series of young boys Sukhareva observed a distinct pattern of difference in emotional sensitivity including "deeply emotional" attachments, "gentle and sensitive" and "tenderly loving" behaviour towards others, and overall a "mixture of insensitive and oversensitive" (Wolff, 1996; pp. 128-129) emotional expression. The characteristics that we now associate with alexithymia were also identified by Sukhareva (for example, "flattened" affect (Wolff, 1996; p. 125); "superficiality of emotions" (Wolff, 1996; p.129)), as was exaggerated emotional sensitivity in some of the boys in their social interactions, providing early evidence for the co-existence of both empathy and alexithymia in autism.

Current-day studies consistently demonstrate that there is no difference in empathic abilities between autistic individuals and typically developing controls (Bird et al., 2010). When alexithymia is controlled for, emotion recognition and empathy may be less accurate but affect sharing, the ability to perceive and match another's emotional state and perhaps a more appropriate measure of empathy, is evident suggesting that autistic people do indeed share what they perceive to be the feelings of others with whom they are interacting (Santiesteban et al., 2021). However, our understanding of the trajectory of autistic empathic abilities across the lifespan, and particularly in later life, is based on findings mostly pertaining to young and middle-aged adults. Although one review of the empathy in autism literature found that empathic processing may improve with age (Harmsen, 2019), Lever and Guerts (2018) examined autistic individual's self-reported empathy in a sample comprising older adults and found no change with age.

2.3.2 Alexithymia

Alexithymia is a condition characterised by impaired emotion processing, including difficulties with emotional reciprocity, and recognising and describing one's own emotions (Bird & Cook, 2013; Gaigg et al., 2018). It manifests as a lack of empathy which is often mistakenly associated as a core characteristic of autism, but there is a strong evidence base pointing to alexithymia, not lack of empathy, as the culprit for socio-emotional problems in some autistic individuals (Bird & Cook, 2013). The reality is that alexithymia is independent of autism although the two frequently co-occur in up to 50% of autistic people (Kinnaird et al., 2019). Very few studies have taken account of the presence of alexithymia in autism research participants (Hollocks et al., 2019). When it is included, it is predominantly measured without taking into account anxiety and depression – both highly co-occurring conditions in autism – and potential confounds with alexithymia (Kinnaird et al., 2019).

2.4 Context and Environment

Social cognition and affect as well as other social emotions such as guilt, shame and embarrassment, and the appropriate use of them in different social contexts, may be influenced by socio-cultural background, developmental history and social learning (Happé et al., 2017; Norris & Cacioppo, 2007). Over the course of the lifespan individuals may be exposed to a range of other people to model, and to practise or test the accuracy and appropriateness of learned (social) behaviours and emotions in social situations (Happé et al., 2017; Norris & Cacioppo, 2007). That is, the greater the diversity of individuals one is exposed to in day-to-day life the greater the potential for learning social abilities such as empathy, emotion recognition and ToM, and when to use them in social interactions. An inability to deploy emotional expressions in ways that are socially and culturally expected or context-relevant can have significant repercussions and highlights how impairments in these social and emotional processes can lead to poor functioning and social outcomes (Norris & Cacioppo, 2007).

It has been recognised that how all these aspects of social cognition come together to form "social skills" resulting in either productive or awkward social interactions is hard to pin down given the wide variability in individual as well as relational abilities of autistic people and their typically developing interaction partners (Morrison, DeBrabander, Jones, Ackerman, et al., 2020). What's more, current measures of autistic adults' socio-cognitive abilities are not predictive of their social interaction outcomes. Because lab-based assessments of social cognition cannot capture the dynamic nature of real-world, "in-the-moment" social interactions, they may not be a truly ecologically valid measure of the social abilities of autistic individuals, or the quality or quantity of social interactions (Morrison, DeBrabander, Jones, Ackerman, et al., 2020). In contrast, when autistic individuals' social abilities are examined in-vivo the success or otherwise of interactions depends on the fit between the individuals involved and the environment (Morrison, DeBrabander, Jones, Faso, et al., 2020). For instance, a study using ecological momentary assessment (EMA) technology to measure social behaviour as it occurs in everyday life found that the number of social interactions were the same for autistic individuals as they were for their neurotypical peers, irrespective of gender or age (Gerber et al., 2019). While social difficulties themselves may not improve, the way autistic adults learn to cope with them might (Bastiaansen et al., 2011). Research has revealed a wide range of self-initiated strategies and external supports, many of which are used by autistic adults to enhance social interactions and manage identified vulnerabilities (Müller et al., 2008). Individual and environmental factors, such as family support and adult-appropriate interventions, may play a role in patterns of improvements in social functioning over time (Shattuck et al., 2007) resulting in relative life success for some (James et al., 2006) but physical and mental repercussions for others (Bradley et al., 2021).

2.5 Social Strategies

In the face of the social functioning difficulties that are a hallmark of autism spectrum conditions, many autistic individuals apply a variety of creative problem-solving strategies to social relationships and interactions (Tantam, 2016). In recent years the explosion of research activity around “social adaptation” (Kanner, 1972) has resulted in a plethora of terms, ranging from coping strategies to compensation, camouflaging, masking and more recently “passing” or “passing as non-autistic” (Libsack et al., 2021), to describe compensatory social strategies autistic people use to appear ‘neurotypical’ (Fombonne, 2020; Hull et al., 2017). Two alternative theoretical frameworks recently developed to guide research in this area differ on whether “camouflaging” or “compensation” is the over-arching umbrella construct representing autistic social adaptation (Hull et al., 2017; Livingston & Happé, 2017) suggesting that conceptually this area of investigation is still in a relative state of flux. Nonetheless, both constructs have been positioned within a neurodevelopmental framework to describe a variety of behaviours and strategies used by autistic individuals to make up for a discrepancy between perceived social ability and actual ability. That is, as defined by Livingston and Happé (2017), compensating autistic individuals engage in outward social behaviours to adapt to the world around them in ways that are better than would be expected given their underlying socio-communication difficulties. Interestingly, this definition echoes the literature on resilience which is understood to be characterised by “functioning that is relatively better than that shown by others experiencing the same level of adversity” (Rutter, 2012; p. 341). By comparison, autistic ‘camouflaging’ is often used in the literature as an umbrella term that encapsulates ‘compensation’ in social environments (Cook et al., 2021). There has been a rapid increase in empirical research investigating the psychological conceptualisation and mechanics of compensatory social coping strategies, particularly camouflaging (Fombonne, 2020), and why some autistic adults use them successfully and others less so. For instance, in the case of camouflaging, Lai and colleagues (2020) propose that there might be distinctly different types of people who camouflage, including those who embrace it and do so with success; those who despite wanting to camouflage are unable to do so; those who see no need to camouflage; and those who are unaware of it altogether as a social tool.

More broadly, there are a range of reasons autistic people use compensatory social strategies. Some are highly motivated to do so because they enhance social functioning and assist in forming relationships that are rewarding, while others find them useful for pragmatic reasons such as pursuing employment opportunities (Bradley et al., 2021; Livingston et al., 2019b). Others do so to suppress autistic behaviours, avoid negative social evaluation (Miller et al., 2021) or bullying and retaliation (Cage & Troxell-Whitman, 2019). There seem to be some gender differences in the reasons for and choice of social strategies with girls and women tending to choose special interests that are more socially conventional (Howlin, 2021). Both late-diagnosed men and women report being more likely to camouflage for functional reasons, such as blending in in the workplace, than for the sake of social relationships, although it is a greater motivation for women than men, perhaps in response to stronger societal pressures on women with regard to gender roles (Bargiela et al., 2016; Cage & Troxell-Whitman, 2019).

Clinicians have long been aware of a variety of social strategies used by autistic individuals from childhood to compensate for perceived social difficulties, to fit in with peers, and to avoid the negative consequences of social errors. Higher intellectual abilities or better executive functioning enable some autistic individuals to monitor and regulate social behaviour (Livingston & Happé, 2017). For instance, intellect, rather than social intuition, is harnessed to observe social interactions and others' behaviours to ascertain and deploy the correct behaviour in certain situations (Attwood, 2007; Brugha, 2018) or to selectively seek out social situations and work environments with predictable structure or low social demands (Livingston & Happé, 2017).

Females, in particular, are thought to imitate others or adopt social roles and scripts based on socially adept peers and avoid unwanted attention by being polite and well-behaved (Attwood, 2007). These observations have been supported by self-reports from autistic adults who describe "pretending to be normal" by adopting personas based on observing peers and information gleaned from books and magazines, using social mimicry, masking autistic behaviours, and consciously conforming to traditional gender roles (Bargiela et al., 2016; Milner et al., 2019). While some autistic individuals rely on a partner for social guidance and feedback (Livingston & Happé, 2017), withdrawal from social situations is a strategy used by others (Attwood, 2007). This strategy may be self-protective in the short-term, but will also deprive autistic individuals of opportunities to model and practise the social skills they find difficult whereas those who persevere in these situations may have fewer social difficulties later in life (Tantam, 2016).

However, the use of camouflaging and other compensatory behaviours is not autism-specific. A number of studies (Hull et al., 2020; Jorgenson et al., 2020; Livingston et al., 2020; Miller et al., 2021) have found no or only small differences between autistic and typically developing individuals' use of compensatory strategies such as masking and camouflaging. Neurotypical individuals reported using masking more than autistic peers (Jorgenson et al., 2020) but use was context dependent: both autistic and neurotypical people masked for social affiliation purposes – that is, to signal to others like-mindedness or a similarity in interests – but only autistic people used masking to minimise or avoid social stigma (Miller et al., 2021). Thus, it may be that the difference in use of these strategies is that for autistic individuals they are in some ways uniquely challenging. While for some compensatory behaviours can help enhance social functioning and quality of life through the attainment of important short-term life goals such as employment and relationships, for others there is risk of exhaustion, stress and mental health problems that can result in less social interaction and lower quality of life (Bradley et al., 2021; Kim & Bottema-Beutal, 2019).

While the earliest literature on autism presented social adaptation as a positive factor in the relative success of more intellectually able autistic people (Asperger, 1991; Kanner, 1972) there is now debate about whether it is an adaptive coping strategy, or maladaptive due to a range of reported negative implications associated with it. Much of the literature today presents camouflaging and other coping strategies, learned in childhood, or explicitly taught through social skills training (Fombonne, 2020) and maintained throughout life, as being in most cases more harmful than helpful (Hull et al., 2021; Livingston & Happé, 2017). Consequences of compensation can be mixed, ranging from enhanced confidence and connectedness to inability to translate acquaintanceship to friendship, a loss of sense of self and difficulty in establishing an authentic self-identity and self-acceptance (Attwood, 2007; Livingston et al., 2019b). Some compensatory social strategies are thought to be ‘shallow’ or superficial, which exposes autistic individuals to failure in novel or fast-paced social situations or if their cognitive resources are compromised by stress or mental health problems (Livingstone & Happé, 2017). Because there is a reliance on intellect and executive functioning skills, which can be effortful and taxing for some (Livingston et al., 2019b), compensatory behaviours, particularly camouflaging, have also been found to be associated with less social interaction, greater stress, physical and mental health problems, and suicidality (for detailed discussions see Bradley et al., 2021; Cage & Troxell-Whitman, 2019; Cassidy et al., 2018; Hull et al., 2017; Hull et al., 2021; Lai et al., 2017).

2.6 Social Functioning and Quality of Life

Social abilities more than other factors are associated with quality of life (Kandalaft & deBrabander, 2021). Some autistic adults’ failure to meet peer social expectations or acquire the necessary abilities to successfully form and maintain adult relationships across a range of contexts from home to work can lead to poor outcomes (Pallathra et al., 2018) and poorer quality of life leading to stress and social withdrawal (Bishop-Fitzpatrick et al., 2018). Those with better developed social skills seem to be protected from social stigma and prejudice thus allowing them to achieve typical adulthood milestones (e.g., employment, partner relationships) (Kim & Bottema-Beutal, 2019) and better quality of life.

As with so much about autism, the findings of studies investigating the factors that contribute to social functioning and outcomes for autistic adults are mixed, possibly because there are a number of cascading effects associated with social communication difficulties (Zheng et al., 2020) that result in varying degrees of difficulty for autistic adults across a range of life experiences. For instance, autistic adults report experiencing social settings as more distressing than their neurotypical peers (Yarar et al., 2020). Higher levels of perceived stress are associated with social disability which in turn, creating a circular problem, impacts negatively on social functioning (Bishop-Fitzpatrick, Minshew et al., 2017). Adults on the spectrum are also more likely to be unemployed or under-employed relative to their skills and abilities (Howlin, 2021; Lord et al., 2020), and experience social aspects of the workplace as stressful (Hickey et al., 2018). Difficulties with social functioning are often implicated in other difficulties such as social disengagement and lack of social networks (Wise, 2019). For some autistic individuals, unfulfilled desire for social interaction or peer rejection can lead to loneliness (Mazurek, 2014) and depression (Smith & White, 2020), anxiety (Hollocks et al., 2019; Howlin & Magiati, 2017) and suicidality (Cassidy et al, 2018; Lai & Baron-Cohen, 2015), particularly for those for whom social communication is also challenging (Smith & White, 2020).

Other factors are associated with more positive outcomes. Inclusive educational and social experiences, such as inclusion in mainstream schools or vocational programs, are thought to play an important role in social communicative development across the lifespan because they provide opportunities for extending the range of experiences and practise opportunities for social interaction (Kandalaft & DeBrabander, 2021; Simonoff et al., 2020). There is also evidence for the influence of positive family processes in encouraging behavioural plasticity that leads to longer-term positive developmental trajectories into adulthood (Woodman et al., 2016). Higher levels of self-determination, autonomy and an ability to self-regulate have also been associated with greater social participation (Kim, 2019). Other factors, such as being in a close personal relationship (Mason et al., 2018) or having access to informal support from family members, friends and acquaintances provides positive experiences and naturalistic opportunities to develop and practice social skills that can be generalised to other social settings (Tobin et al., 2014; Woodman et al., 2016). Formal supports such as social skills groups, community support groups and organised recreational activities that provide opportunities for social participation help minimise stress, reduce loneliness and isolation thus benefitting social functioning and quality of life (Bishop-Fitzpatrick et al., 2017; Tobin et al., 2014). However, although autistic adults who report higher levels of social support also report better quality of life (Bishop-Fitzpatrick et al., 2018), they nonetheless report significantly lower levels of social support than typically developing adults, indicating they are aware of their relatively limited social connectedness (Gaigg et al., 2020). It is likely that for autistic adults establishing social support networks in the first place is difficult due to social communication impairments and, for many, the stressful nature of social interactions (Gaigg et al., 2020) not just because of individual characteristics but also as a result of poor fit with the social environment (Morrison, DeBrabander, Jones, Faso et al., 2020). Indeed, a deep understanding of the separate and combined influence of individual, family and environmental factors on social outcomes and wellbeing for autistic individuals is still some way away, and that is particularly the case for older autistic adults (Howlin & Magiati, 2017).

2.7 Social Functioning in Older Autistic Adults

The dearth of research on social and emotional ageing in autism is in stark contrast to the considerable literature on these aspects of typical ageing in the fields of lifespan developmental psychology and geropsychology. This is despite recent research attention on both ageing in autism and aspects of social functioning, particularly the current “hot topics” of social cognition, camouflaging and other compensatory behaviours that are thought to have contributed to the late diagnosis of older adults (Happé & Frith, 2020, Howlin, 2021, Lord et al., 2020). However relatively little is known about how the two intersect – that is, the developmental trajectory of social functioning in older adults with autism. While on the one hand older age has been found to be associated with better social functioning in autism (Bishop-Fitzpatrick, Mazefsky et al., 2017) it is thought that declining physical and mental health, also associated with older age in autistic adults (Sonido et al., 2020), may have a negative impact on social functioning (Howlin & Magiati, 2017). Loss of support, inflexibility in the face of changing social situations, and reluctance to engage socially (Mason et al., 2018) have also been identified as factors potentially relevant to older autistic adults’ social functioning, although one of the few studies of older adults over the age of 50 (M_{age} = 70) found that participants with high ASC characteristics did not have smaller social networks or a history of more negative life events than those with a lower level of autistic characteristics (Geurts et al., 2016). Nonetheless, it is not well understood if social functioning experiences in older adults are similar to those experienced at earlier life stages, whether or how social functioning changes over the life span, and if it does whether its developmental trajectory is similar to that of typically developing adults in later life.

Like so many aspects of autistic experience, what is known about social functioning, the various components discussed above, and their trajectory over the lifespan, is mostly based on research with young and middle-aged adult participant samples aged under 50 years (Mason et al., 2021) diagnosed according to earlier more restrictive diagnostic criteria by which late-diagnosed adults would not have been identified (Henninger & Taylor, 2013; Howlin, 2021), and with varying levels of social and intellectual ability and clinical "need". Very few studies include participants aged over 60 (Howlin & Magiati, 2017). Perhaps unsurprisingly, the findings are mixed. Whereas Lever and Geurts (2018) found self-reported ratings of ASD traits, including social difficulties, peaked in middle age (M_{age} = 47.9 years) but were lower in older adults (M_{age} = 63.7 years), some studies point to improvements in social functioning over time but no change in autistic symptoms (age range 18 to 54 years; Bastiaansen et al., 2011), while others find the reverse (age range 10 to 52 years; Shattuck et al., 2007). However, a 40-year follow-up study (Howlin et al., 2013) of a clinical sample of middle-aged autistic adults (age range at initial assessment 16 to 45 years and at follow-up 37 to 64 years) found that while there was an improvement in autism symptoms, social functioning remained poor, and in some cases had worsened. Overall, social outcomes for these participants contributed to a litany of examples of disadvantage and poor quality of life: minimal social integration; high unemployment; inadequate financial resources; minimal social services support; and failure to form friendships or intimate relationships. The heterogeneity of the mostly middle-aged participant samples in these studies, and their inconsistent and somewhat conflicting findings, reflect a similar broader trend in research on trajectories of change in social functioning in autism over the lifespan (Howlin & Magiati, 2017).

More recently, some work in the areas of social support and social cognition in older autistic adults has emerged. An examination of the associations between social support and QoL in middle-aged and older autistic adults (mean age = 52.19 years) undertaken by Charlton, McQuaid and Wallace (2023) found that, even when demographic, physical and mental health factors were controlled for, better quality of life was associated with social support as it is in typically developing older adults. Three types of support were measured, including the quality and quantity of social interactions, objective measures of assistance in everyday life, and subjective assessment of the quality of close relationships, but it was subjective social support that was particularly associated with all aspects of QoL. The authors noted that this finding was consistent with findings in younger autistic and older non-autistic samples but did not explore the possibility that this finding might be evidence for a trend similar to that seen in typical ageing whereby peripheral or novel social partners are selectively excluded in preference for (subjectively) emotionally close ones that are more rewarding (Carstensen et al., 1999).

Lever and Geurts (2016a) found that ToM did not deteriorate with age, and that older autistic adults (M_{age} = 60.8 years) did not exhibit greater ToM impairment than matched typically developing controls. They also found significantly fewer older (M_{age} = 63.7 years) than young and middle-aged (M_{age} = 47.9 years) autistic adults experienced social anxiety (Lever & Geurts, 2016b). More recently, Yarar and colleagues (2020) also investigated the trajectory of age-related social cognition abilities in autistic compared to typically developing adults. They found autistic older (M_{age} = 61.32 years) and younger (M_{age} = 29.48 years) adults performed more poorly than TD adults on all measures of ToM, alexithymia and empathy. However, unlike TD adults, older autistic adults' performance did not differ from younger autistic adults on ToM suggesting that in contrast to normative ageing, ToM does not decline with age in autism. The authors speculated that this pattern may reflect benefits to autistic individuals of ongoing use of compensatory social skill strategies across the lifespan. Alternatively, sustained practice of these strategies may confer protection against cognitive decline. Empathy was unaffected by age effects, with young and old ASC adults reporting less empathic concern, less successfully taking the perspective others, and feeling more personal distress in tense social situations than TD adults. However, although autistic adults self-reported higher levels of alexithymia than TD controls, when this was covaried in the analyses, there was no difference between ASC and TD groups on empathy (with the exception of perspective taking), suggesting that difficulties with empathy are attributable to alexithymia not autism across the lifespan and into in later life.

However, despite this small body of emerging research social functioning in later life is still relatively understudied. Difficulties in the social domain are usually noted in both general reviews of autism research and more specific reviews of ageing in autism, but in most the focus is on diagnostic, cognitive or quality of life and wellbeing contexts of ageing in autism, and social functioning is not identified as a discrete area of focus for future research (See, Happé & Charlton, 2011; Happé & Frith, 2020; Howlin, 2021; Piven & Rabins, 2011; Sonido et al., 2020; Wise, 2019). Despite its ubiquity in overall functioning as a core characteristic of autism, social functioning and its components is mostly identified as a secondary issue in the context of social support needs, services and outcomes rather than identified as an area of ageing that might in and of itself warrant focused attention.

2.8 Older Autistic Adults' Experiences of Social Functioning

Most of what is known about older adults on the autism spectrum is drawn from autistic individuals' written stories (for example, Grandin, 2006; Michael, 2016, 2021), case series (James et al., 2006; van Niekerk et al., 2011) and qualitative studies (Hickey et al., 2018). Qualitative research is increasingly used as a methodology to explore autistic experiences in the context of a range of individual and environmental factors that affect their everyday lives, including – but to a lesser extent – experiences of ageing. It is regarded as a research methodology well-placed to explore the complexities of autistic adults' motivations and experiences of social functioning (Livingston et al., 2019b) and other aspects of autistic experience. Themes relating to issues of social functioning run like a thread through qualitative studies and first-person accounts. However, again, with the exception of a few, most studies' explorations of social functioning in adults report on predominantly young and middle-aged adults and suggest common themes of social and communication difficulties, as would be expected, but also social isolation, a desire for friendship and intimacy but hesitation and fear about what close relationships might lead to, pleasure in community and volunteer activities, and a deliberate and effortful focus on developing social and self-awareness that was perceived to have resulted in improved social understanding (Müller et al., 2008)

It seems likely that the experiences of adults 50 years and older, with at least a couple of decades more life experience, will be different. However, Hickey and colleagues' (2018) exploration of the lived experience of autism in later adulthood found most participants (M_{age} = 60.3 years) longed for social connection, with loneliness and social isolation reported as longstanding and omnipresent throughout their lives. This sense of disconnection was characterised as a defining feature of ageing with autism. Some longed to have a close emotional partner and those who did felt it eased but did not totally remove a fundamental sense of innate isolation. Many participants were unemployed, but for those who weren't social aspects of employment were experienced as stressful, and retirement was a relief insofar as the transition brought with it a narrowing of social opportunities and networks. The authors, noting that the findings of their study lacked obvious life-stage specific themes, speculated that the similarities in experience of this older sample of autistic adults with findings from younger samples (e.g., unemployment, lack of close emotional partners) might be evidence that autistic adults do not progress through distinct life transitions and stages the same way typically developing adults do.

Taking a different research perspective, The Australian Longitudinal Study of Adults with Autism (ALSAA) investigated what "ageing well" meant to autistic adults (M_{age} = 50.3 years) and their carers (Hwang et al., 2017). Again, social networks, social skills and social isolation were all themes identified but so too was a preference for smaller friendships groups. While some valued the close emotional relationships of family, and others preferred independence and lack of familial dependents, developing social skills and learning how to relate to others was reported as necessary for ageing well, although the importance of two-way understanding was also noted by many participants.

Finally, Temple Grandin, perhaps one of the world's best known older autistic people, has used her profile to reinforce that autism is a lifelong condition. She has written and spoken at length about her personal experience of autism across the lifespan (Grandin, 2006). She reports social interactions have always been difficult and remain so. Her experience is that social skills are learned not instinctual, and the "rules" of social interaction must be taught just like spelling. She quotes Hans Asperger's view that "social adaptation has to proceed via intellect".

2.9 Rationale and Aim

Difficulties with social interaction and communication are at the core of autism spectrum conditions however there is still much to be learned about the trajectory of social functioning over the lifespan (Howlin, 2021), particularly from the perspective of autistic adults themselves. As the review in this chapter demonstrates, although there is a growing body of both quantitative and qualitative research on a range of social components thought to influence social functioning, a key limitation is that the focus has predominantly been on young and middle-aged autistic adults. Consequently, what is not well understood is social functioning in older autistic adults: whether or how it changes over the life span, and if it does whether its developmental trajectory corresponds to that of typically developing adults in later life. This represents a clear gap in the literature. What is needed is a focused exploration of autistic experiences of social functioning in later life to enhance our understanding of this critical life stage and the individual, social and environmental factors that may contribute to or threaten the wellbeing of older adults on the autism spectrum. Indeed, as Lorna Wing (2005) pointed out, an examination of the profile of skills and abilities of individuals may be a better foundation for the development of helpful supports for people on the autism spectrum. Therefore, one of the aims of the current program of research was to explore qualitatively the personal experiences of older autistic adults in relation to changes in social functioning over the lifespan.

Chapter 3: What is Successful Ageing and What Factors Might Influence it in Autism?

3.1 Successful Ageing

As autism research extends its focus beyond diagnosis and interventions, insights from gerontological and geriatric research on ageing in the general population, and ageing with autism in the context of normative life milestones (e.g., marriage, grandparenthood), might be useful. This approach has been called for by other researchers and autism advocates (Edelson et al., 2021) and by older autistic adults themselves (Michael, 2021). Bringing new perspectives and concepts to autism research offers the potential for innovative ideas that might challenge expectations and theories (Rutter, 2005). This happened at the turn of the century when entrenched ideas about sadness, loss and shrinking social networks often associated with typical ageing were challenged by evidence of a paradox of ageing – that in later life people are generally more satisfied with life and enjoy relatively higher levels of emotional well-being (Carstensen, 2021; Charles & Carstensen, 2010).

This paradox of ageing is characterised by a more positive outlook on life. A longitudinal study by Laura Carstensen and colleagues (2011) using experience sampling to track changes over a ten-year period, recorded emotional experiences as they occurred in the course of daily life and found that, as people aged, they experienced positive emotions more frequently than negative emotions. What's more, people who experienced positive emotions had better quality of life and lived longer. The authors also found that a co-occurrence of the two emotions contributed to an overall stabilisation in their emotional experiences, and poignancy, a simultaneous mix of positive and negative emotions (e.g., "bittersweet" moments in life that are both joyful and sad; gratitude tinged with a sense of fragility), also increased. The authors argued that this contributes to emotional stability which is also related to wellbeing and improvement in quality of life. Other studies have consistently provided evidence for the "positivity effect" in ageing, characterised by older adults' bias towards positive rather than negative information compared to younger adults (Reed et al., 2014). Older adults demonstrate an ability to appraise their strengths and weaknesses realistically and with a strong emphasis on resilience and optimism which are strongly associated with self-rated successful ageing (Jeste et al., 2013). However, the positivity effect is more likely in those people who have higher levels of executive control (Sims et al., 2015) and can be eliminated when positive and negative information are jostling at times of critical decision-making.

Typically developing older adults have also been found to draw on life experience and long-practised strategies to flexibly, effectively and efficiently adapt problem solving and emotion regulation strategies according to the context (Blanchard-Fields, 2009; Kunzmann & Isaacowitz, 2017; Springstein et al., 2022). Self-acceptance and interdependence are also important for wellbeing in later life; older adults' reliance on others at times is necessary, and indeed inevitable, for human flourishing and successful ageing (Baltes & Baltes, 1990; Ng et al., 2020). Lifespan developmental models based on the conceptualisation of successful ageing as a process of adaptation or behavioural plasticity frame these findings as evidence of later life social and emotional developmental gains through selection, optimisation and compensation (Baltes & Baltes, 1990), and the perception of constraints on time left to live as motivation for prioritising a focus on the present rather than the future (Carstensen et al., 1999; Carstensen et al., 2011; Charles & Carstensen, 2010).

Like autism spectrum disorders, normative healthy ageing is an individual and variable process determined by differences in cognitive, behavioural, and social factors. Healthy ageing is measured according to an individual's functional ability, intrinsic psychological capacity and how the environment in which they live shapes what they can be and do (World Health Organization, 2020). Developmental theories of ageing are based on the premise that humans have an extraordinary ability to compensate and adapt to the world around them, and as such successful ageing is a process of adaptivity or behavioural plasticity (Baltes & Baltes, 1990; Baltes & Carstensen, 2003) – with the right environmental and medical conditions, older adults have the capacity to make gains in social and emotional functioning (Baltes & Baltes, 1990). While ageing might not herald fundamental changes in either – for instance the human need for social belonging is lifelong – there are distinct changes in social and emotional *life* in older adulthood (Charles & Carstensen, 2010).

This chapter will review the critical role of social and emotional functioning in the successful ageing of typically developing adults in the following sections on social ageing and emotional ageing. These sections are intended to provide background and context to Section 3.2 on outcomes and outlook in autism and Section 3.3 which reviews what is known about uniquely autistic experiences associated with diagnosis and emotional functioning, both factors likely to impact on successful ageing. Drawing on the gaps and limitations identified in the literature reviewed in this chapter, the chapter concludes with the associated rationale and aim of this thesis' program of research. Finally, the overarching research questions and thesis aims are restated.

3.1.1 Social Ageing

Social understanding is important to social functioning in successful ageing. Evidence suggests that although socio-cognitive skills may be impaired in older adults, socio-affective abilities remain intact (Reiter et al., 2017). Baltes and Baltes' (1990) metamodel of selective optimisation with compensation (SOC) sets out a process of adaptation that humans engage in across the lifespan to develop strategies to achieve life goals and age successfully. It incorporates the elements of selection (deliberately narrowing goals and prioritising those that are more meaningful and realistic); optimisation (engaging in behaviours that optimise abilities and functioning), and compensation (the adoption of strategies to address reduced abilities in order to function adequately and achieve goals). Goal selection is an adaptive process in lifespan development and ageing that involves individual selection and focus on domains that are most important and that align with a convergence of environmental demands, personal motivational levels, and abilities (Baltes & Baltes, 1990).

Goal selection is critical in the social domain according to socioemotional selectivity theory (SST; Carstensen et al., 1999). As older adults perceive that time left to live is diminishing, they alter their social behaviour and seek to restructure their social world to maximise life goals that satisfy emotional needs. Thus, social life changes in typically developing older adults in a number of ways – there is a narrowing of social networks, qualitative and quantitative changes in social roles, and a prioritisation of meaningful relationships (Charles & Carstensen, 2010). In later life, social relationships and connectedness, and particularly the types of social interaction, are critically important for affective well-being (Carstensen et al., 2003) precipitating a change in older adults' social behaviour that is characterised by an increased discrimination in the choice of social partners (Fredrickson & Carstensen, 1990). To achieve this, older adults selectively prune social networks of peripheral social partners in favour of family and close emotional partners and friends because they derive greater emotional satisfaction from them (Carstensen et al., 2003) and this emotional reward outweighs the potential costs of investing time in less emotionally important social partners or interactions (Fredrickson & Carstensen, 1990). A benefit of older adults' narrower social networks is that they are associated with better emotional tone (i.e., they elicit fewer negative and more positive emotions) which, unlike network size, predicts daily emotional experience (English & Carstensen, 2014).

Social interactions are engaged in and navigated to maintain emotional stability and avoid negative experiences. Social activities are chosen carefully according to their personal and emotional meaningfulness (Carstensen & Charles, 2010). Although less social interaction seems counterintuitive because social support is strongly positively associated with wellbeing, this deliberate strategy to structure the social environment serves to ensure predictability, less social conflict, and greater control over how others engage with them (Sims et al., 2015). In this context, according to SOC and SST, limiting social contact is an adaptive strategy that enhances emotional wellbeing (Baltes & Carstensen, 2003) because smaller social networks comprising familiar or emotionally close family and friends benefits mental health (Charles & Carstensen, 2010). Selective social interaction is beneficial in other ways. Older adults who provide social support to others rather than receiving it report more positive emotions including feeling a greater sense of purpose (Carstensen & Charles, 2010). Typically developing older adults report that social inclusion, having social roles and being involved in activities, are important to ageing well (Bowling, 2006).

3.1.2 Emotional Ageing

In the gerontological literature, the concept of emotional ageing refers to a pattern of change in emotional experiences that typically occur with age. Contrary to ageing stereotypes, emotional ageing is characterised by a steady improvement in emotional experiences from early adulthood into old age, including higher levels of emotional wellbeing, greater emotional complexity (i.e., co-occurring positive and negative emotions), reduced rates of mental health problems, and greater emotional stability (Carstensen et al., 2011; Charles & Carstensen, 2010). This later life improvement in emotional wellbeing is another aspect of the ‘paradox of ageing’ (Charles & Carstensen, 2010). Again, SST explains this phenomenon as the result of later life changes in the perception of time – the realisation that time left to live is less than the time already lived – which prompts the use of selection as an effective emotion regulation strategy (Sims et al., 2015) whereby the focus becomes emotionally meaningful goals and relationships in the present rather than knowledge-related or future goals. Combined with a deliberate pruning of social networks, this shift in emotional regulation is believed to benefit late-life mental health and emotional wellbeing (Carstensen et al., 1999; Carstensen et al., 2011). Context is important too: life experience in managing emotions, avoiding negative experiences and stressors, and the development of self-knowledge, resilience and wisdom over the lifespan are also believed to contribute to effective emotional regulation in successful ageing (Charles & Carstensen, 2010; Diehl & Wahl, 2020; Jeste et al., 2013; Reichstadt et al., 2010; Springstein et al., 2022). Nonetheless, not all typically developing older adults attain affective wellbeing and emotional stability in later life; individual differences in disposition, life events and how they are managed may influence emotional ageing (Scheibe & Carstensen, 2010). Social selectivity, and the emotional benefits it confers in old age, may be less possible when there is social isolation, loneliness, or in the face of unavoidable or unexpected stressors that trigger distressing or unpleasant events across more than one life domain (Sims et al., 2015). In these situations, it may be more effortful for older than younger adults to regulate negative emotions (Charles, 2010; Diehl & Wahl, 2020), particularly when selectivity is not a viable option (Sims et al., 2015). For instance, although trends in loneliness across the lifespan suggest it is at its lowest in later life, especially in the 60s (Nguyen et al., 2020), death of a romantic partner, close friend or family member can result in a loss of social belonging resulting in social isolation, loneliness and ultimately depression (Charles, 2010; Charles & Carstensen, 2010; Courtin & Knapp, 2017). Social isolation and loneliness are risk factors for older adults whose social network is too small (Charles & Carstensen, 2010); particularly if they do not have a nuclear family or at least a few close relationships (Sims et al., 2015). Chronic and pervasive life stressors, such as living with an abusive partner or a functionally limiting health condition, are also problematic for older adults because they disrupt their ability to engage in age-related adaptive social behaviours that promote emotion regulation (Charles, 2010).

There is a vast body of evidence for the applicability of these models to later life outcomes in various cultures (Carstensen et al., 2003) as well as other neurodevelopmental disorders such as schizophrenia (Jeste et al., 2011) although they have not been considered in the context of ageing in autism: there is virtually no literature on older autistic adults' "everyday" outlook on life and the future. As described above, recent working groups in autism and ageing research have identified issues of concern and priority research areas that predominantly focus on cognitive and health related aspects of autism. Research on these issues is vital as they are of primary concern to autistic adults and their families and supporters and will guide crucial developments at individual, environmental and policy levels for future generations.

3.2 Outcomes and Outlook in Autism

Contributing to the imperative for a better understanding of autism and ageing and associated support needs is that the future for autistic adults, especially in later life, is routinely described in the literature in bleak terms, even though there is some evidence for more positive outcomes in older age (Scheeren et al., 2022). Indeed, research on ageing on the autism spectrum is mostly associated, at both the individual and the research level, with anticipated challenges and the "unknown" (Edelson et al., 2021; Roestorf et al., 2019; Sonido et al., 2020) and a fall-back assumption that problems seen in childhood may simply "ossify" in late adulthood (Stuart-Hamilton & Morgan, 2011). Perhaps this is not surprising given that a recent meta-analysis of outcome studies revealed that just under 50 per cent of autistic adults were rated as having a poor outcome (Mason et al., 2021). But as with so many areas of autism research, evidence on autistic outcomes is mixed. Objective measures such as employment, independence, social participation and relationships reveal concerningly high levels of economic, educational and social disadvantage, and limited numbers of social contacts (Henninger & Taylor, 2013; Howlin & Magiati, 2017; Mason et al., 2021). However, there are discrepancies between objective and subjective measures of quality of life and outcomes for autistic individuals (McCauley et al., 2020) and considerable heterogeneity in their criteria (Lord et al., 2020), as evidenced by Scheeren et al.'s (2022) more positive finding that in a sample of autistic adults with average cognitive functioning 86 per cent had fair to good objective psychosocial outcomes. Much research on outcomes has focused on intra-individual determinants (e.g., IQ), with little exploration of the contribution of familial and contextual (e.g., socio-economic status) factors meaning that findings are inconsistent and sometimes contradictory (Howlin & Magiati, 2017; Mason et al., 2021). Quality of life is considered an important measure of outcome but there is little evidence for the construct validity of most QoL measures used for autistic adults (Ayres et. al., 2018; Williams et al., 2023). Indeed, there is a broad range across studies in terms of the predictors typically used to measure adult outcome (e.g., ranging from autistic symptomology and IQ through to relationships, employment and level of independence), which makes it difficult to discern an overall picture of autistic "outcome", and it is likely that important contributing variables to QoL in autistic adults have not yet been identified (Charlton et al., 2023; McConachie et al., 2018). For instance, some studies have found that overall quality of life is poorer for autistic individuals than the general population (van Heijst & Geurts, 2015), but others have found that poorer subjective QoL in autistic individuals observed at the group level is not reflected at the individual level where QoL is experienced as subjectively good (Oakley et al., 2021). There are also contradictions about the role of age in QoL, with some studies finding it is independent of age (van Heijst & Geurts, 2015), others that older age predicts lower social and psychological quality of life (Mason et al., 2018), and yet others finding the reverse, that older adults report higher social, psychological and overall QoL satisfaction than younger autistic adults and greater subjective wellbeing (Roestorf, et al., 2022; Yarar et al., 2022). The age of samples – and their life stage – also complicates identifying and comparing which predictors play a role at different stages of life, with autistic traits and associated symptoms (e.g., mental and physical health problems) influencing quality of life in different ways at different developmental stages (Oakley et al., 2021). However, the potential influence of developmental life stage on quality of life has not been given much consideration in autism research (van Heijst & Guerts, 2015). An example of this is Roestorf et al.'s (2022) longitudinal investigation of respective differences in QoL in younger (age range 31.89 to 36.23 years) and older (age range 58.61 to 60.94 years) autistic adults. The authors found that there was not a significant change in self-reported QoL over a two-year period within either group but failed to explore potential explanations for the significant difference in scores *between* the younger and older groups at both time points. Yarar et al. (2022), who found a similar pattern in older (M_{age} = 57.88 years) compared to younger (M_{age} = 31.03 years) autistic adults, suggested cohort or "survivor" effects might explain this phenomenon, but similar patterns in typical ageing might also be useful as a point of reference to help expand our understanding of the developmental trajectory of autism, as might autistic adults' own descriptions of their quality of life, a perspective that is currently lacking in the research literature (Charlton et al., 2023).

An additional complication is that there is a lack of consensus on what constitutes good outcomes (Lounds Taylor, 2017) and how differences in the developmental trajectory of autism might influence different pathways to different outcomes (Lord et al., 2020). It is difficult to find consensus on what factors influence wellbeing and quality of life, and outcomes are often not based on autistic individuals' notions of success which might be different from traditional (typical) notions or benchmarks (Webster & Garvis, 2017; 2020). There is enormous heterogeneity in terms of what individuals prioritise as being of importance to them, and these priorities may be confounded or not consistent with researchers' expectations and value-based decisions about what constitutes a good outcome or is a useful indicator of general quality of life, wellbeing and life satisfaction (Lounds Taylor, 2017; McConachie et al., 2018). Recent reviews and working groups including autistic collaborators all agree that much more research on all aspects of autistic ageing is needed. These groups have identified priorities for ensuring quality of life for older adults on the autism spectrum focus on a mix of cognitive, instrumental (practical or functional), and psychological factors. Roestorf et al. (2019) reported on special interest group meetings of many research groups from the UK, Europe and the US. The focus of this group was on cognitive and physical changes in ageing rather than developmental transitions. Autistic traits and diagnosis in later life, issues pertaining to cognitive ageing, assessment and background medical and diagnostic history, and wellbeing and quality of life were highlighted research topics. Sonido et al. (2020) also focused on research challenges associated with diagnosis in older adults as well as identification of older autistic adults for participation in research studies to ensure validity. Ensuring inclusive research practices give voice to older adults' experiences particularly in relation to sensitive topics such as residential aged care choices and preferences and healthcare needs were also nominated as important areas of future research. More recently Edelson and colleagues (2021) formed a think tank on ageing and autism that identified a wide range of research opportunities for addressing personal needs and concerns identified by attending autistic adults. These included independence in later life, transitioning to retirement and potential associated loss of social connection, loss of support from family over time, and individual resilience. Many of the areas of focus of these reviews have a biomedical emphasis on outcomes and quality of life in terms of physical and mental/cognitive functioning.

Involvement of autistic voices is important in identifying which components might contribute to a good outcome in later life, as they may not align with neurotypical views (Howlin, 2021). But, although autism research is increasingly turning its attention to *outcomes* for adults on the autism spectrum, there has been comparatively little exploration of older autistic adults' experiences and *outlook* on life now or for the future. Lay perspectives are vital for ensuring that research programs have social significance and reflect the multidimensionality of ageing (Bowling, 2007; Wahl et al., 2017). Results from one of the few qualitative studies to explore lived experiences of autism in later life revealed older adults felt a sense of self-acceptance and compassion in later life, particularly after receiving their diagnosis (Hickey et al., 2018). Some participants in this study noted that they felt less social pressure as they aged, and they reported wondering if this was a positive outcome of their diagnosis, or if life would have been less stressful anyway as they aged. Although a longing for social connection was ongoing into later life for these participants a number found social aspects of employment stressful and for many, in contrast to some of the concerns raised by Edelson et al., (2021), retirement was a relief insofar as it brought with it a narrowing of social networks. The authors also noted that participants' focus in interviews was on the present and recent past rather than the future. They speculated this may have been either a result of most participants' relatively recent diagnosis being a more salient life experience or evidence that older autistic adults might not progress through developmental life stages in the same way as typically developing adults do. The authors posited that the study's participants' apparent failure to attain typical life milestones such as the development and maintenance of close emotional relationships, regular ongoing employment and retirement might suggest that autistic adults do not progress through developmental life cycle stages past middle adulthood as do typically developing adults.

Quality of life and successful ageing are closely aligned concepts (Chappell, 2017), with the field of gerontology framing positive outcomes in typically developing older adults in terms of successful ageing or ageing well. In geropsychology successful ageing is multidimensional, including both objective criteria (e.g., biological and mental health, cognitive capacity, length of life) and subjective criteria (e.g., cognitive and emotional wellbeing, mastery and control, fulfilling social relationships) incorporating older adults' personal evaluations of what ageing successfully means to them (Wahl et al., 2017). Interestingly, we are aware of only two studies adopting a gerontological model to examine successful ageing in autistic adults. Noting that current gerontological conceptualisations of ageing, such as Rowe and Kahn's model of ageing well, have not included considerations of developmental disabilities, Hwang and colleagues (2017) used qualitative methodology to investigate autistic adults' (M_{age} = 50.3 years) perspectives on ageing as an important first step in understanding how the concept might apply to autism. Participants reported that being autistic was not a barrier to ageing well, with some personal attributes and qualities perceived as strengths at this stage of life. Individual attributes such as self-concept and life experiences were identified as important resources for successful ageing. Person-centred factors such as the need for informal supports and having fulfilling personal relationships and greater societal understanding and acceptance were also important. But ageing well was perceived as a multifaceted process. Socio-cultural, environmental factors, and relational factors were also identified by participants. Participants reported that healthcare, such as the co-ordinated management of both physical and psychological conditions, housing and employment supports were of particular importance to ageing well. The study's results indicated that a strength-based approach to understanding ageing on the autism spectrum may better encapsulate the needs of autistic adults than Rowe and Kahn's conceptualisation.

These authors conducted a subsequent study that explored the applicability of Rowe and Kahn's model to ageing on the autism spectrum based on the health and functioning of autistic adults (M_{age} = 51.7 years) compared to typically developing adults (Hwang et al., 2020). According to Rowe and Kahn, successful ageing is possible with a combination of three factors: engagement with life; a high level of physical and cognitive functioning; and the avoidance of disability and disease. A large proportion of the study's participants failed to meet these benchmarks. The authors speculated that these factors may not flexibly accommodate known difficulties associated with autism when they were operationalised from a range of health and wellbeing measures (e.g., mental and physical health, daily functioning and activities, social support and autism-related topics) compiled as part of the Australian Longitudinal Study of Adults with Autism (ALSAA). Participants' responses indicated lower levels of social participation, an inverse association between higher AQ scores and the physical and cognitive functioning factor, and higher levels of co-occurring medical conditions. The authors concluded that Rowe and Kahn's focus on health and functioning and failure to adequately accommodate disability in their model reduced its applicability to ageing well with autism. They suggested that broader and more flexible models with a combination of objective and subjective criteria and that could incorporate environmental, psychosocial and uniquely autistic factors would be more useful for theoretically conceptualising ageing in autism. Suggested additions included consideration of compensatory mechanisms, and achievement, maintenance and use of resources and strengths.

Up until now, discussions and research agendas on ageing in autism have been informed in some cases by assumptions and speculation about ageing based on known difficulties and problems with socio-communication difficulties and behaviours in autism in childhood through to middle-age. There is strong evidence for a negativity bias in information processing in youth (Reed et al., 2014) and studies of ageing in autism that draw on evidence from studies using mostly adolescent and young adults may unintentionally be anticipating a negative outlook that is not reflected in older adults' perspectives on life, ageing or autism. Thus, just as reported *outcomes* for mostly middle-aged autistic adults seem bleak, so too might autistic adults' *outlook* on life be grim, particularly for older adults who are reaching a stage of life when additional – and potentially exasperating – declines in cognitive, physical and mental health that are associated with ageing might be anticipated. This may be particularly so because references in the autism literature to ageing in the typically developing population mostly refers to decline and loss (Rose & Michael, 2022). But these fears and concerns may be based on misconceptions about ageing more generally rather than taking into consideration the potential of this stage of life, supported –perhaps counterintuitively, and certainly contrary to negative ageing stereotypes – by a growing body of evidence that old age typically brings with it greater overall wellbeing; a complex mix of happiness, life satisfaction and fulfilment (Eendebak & World Health Organization, 2015) as well as emotional stability and wellbeing (Carstensen et al., 2011; Charles & Carstensen, 2010).

Beyond negative stereotypes, there are perhaps other more practical and autism-specific factors that have the potential to complicate successful ageing in autism. Firstly, older adults with autism have been dubbed the "lost generation" (Lai & Baron-Cohen, 2015). Although autism is a spectrum of lifelong neurodevelopmental conditions, formal diagnostic criteria extending identification of autism to adults was only included for the first time in the 2013 release of DSM-5 (Lai & Baron-Cohen, 2015) meaning many unidentified autistic adults are not aware of autism, and first come to clinical attention later in life due to difficulties with social interaction or for management of co-occurring psychiatric disorders (Jones et al., 2014; Tantam, 2016) which may have overshadowed autism symptoms (Huang et al., 2021). Implicated in late diagnosis, and a fundamental factor in successful ageing, is emotional functioning. In some cases it is emotional problems later in life – stressful life events and transitions or exacerbated mental health problems – that trigger initial help-seeking resulting in a referral for an autism diagnosis (Guerts & Jansen, 2012; James et al., 2006; van Niekerk et al., 2011). Could these uniquely autistic experiences impact successful ageing? What is known about diagnosis and emotional functioning in later life is briefly reviewed in the following sections.

3.3 Factors Impacting Successful Ageing in Autism

3.3.1 Diagnosis

While the first generation of children diagnosed with autism are now entering late adulthood (Sonido et al., 2020), it is likely that most autistic individuals are adults who have never been formally diagnosed (Brugha, 2018; Lord et al., 2020). The world's ageing population means that it is probable that many people living with ASC are in fact not children or adults but elderly adults, a trend that is likely to continue in the years to come (Howlin et al., 2015). However, there are challenges associated with identifying older autistic adults in the population, let alone teasing out the circumstances and barriers leading to their self-identification or diagnosis (Sonido et al., 2020).

Difficulty distinguishing autistic features that are masked by co-occurring psychiatric conditions such as anxiety and depression has been identified as a significant barrier to diagnosis (Happé et al., 2016; Happé & Frith, 2020; Huang et al., 2021). For older autistic adults who present for later-life diagnosis little is known about how they came to the point of diagnosis at this stage of life, their life outcomes, or emotional functioning.

In recent times, with increasing community awareness of ASCs, both delayed diagnosis and self- rather than clinical diagnosis of ASC have become more common in adulthood (Lewis, 2017; Happé et al., 2016). This may be particularly so for adults with milder autistic traits who throughout life have found ways to cope with their difficulties. Some have learned to adapt to the world around them in order to lead relatively successful lives (James et al., 2006), while others' autistic characteristics may have been less obvious due to gender, age, cultural factors or environmental fit (Huang et al., 2021; Lai & Baron-Cohen, 2015; Lai et al., 2020; Volkmar et al., 2021). In some cases, an individual's level of social and emotional functioning may have "protected" them from a diagnosis in earlier life. Variability in socio-communicative symptom profiles and repetitive behaviours, which have altered with time, and ongoing development can also complicate diagnosis (Bal & Lounds Taylor, 2019). What's more, diagnosis based on behavioural symptoms alone may not accommodate differences due to gender, particularly for women (Milner et al., 2019). General Practitioners (GPs) are often the first health professionals consulted for assistance by undiagnosed autistic adults (Jones et al., 2014), but many report limited experience or training in autism and autism diagnosis and a lack of skills and confidence in identifying or managing the healthcare needs of autistic adults in their care (Unigwe et al., 2017; Zerbo et al., 2015). While it is the case that for autistic adults a detailed clinical interview with a specifically trained health professional is a more appropriate diagnositic method (Brugha, 2018), access to specialists in autism can be complicated by complex healthcare systems and a lack of clear referral pathways (Bradshaw et al., 2019; Lewis, 2017; Sonido et al., 2020). Thus, before, or rather than, seeking a diagnosis, some individuals rely on self-diagnosis (Brugha, 2018).

Pathways to, and acceptance of, an ASC diagnosis as an adult are varied and associated with a number of other barriers. For individuals whose understanding of ASCs was based on earlier diagnostic criteria relating to lack of language or intellectual impairment, or for those who are simply unaware of autism or how it manifests, the notion that they too might have an ASC may not have occurred to them (Jones et al., 2014). Other barriers include individuals' concerns that in seeking a diagnosis they will not be believed by health professionals, difficulties in adequately communicating symptoms, and fears about the potential stereotypes and stigma associated with diagnosis and autism-related language and labels (Bury et al., 2020; Huang et al., 2022; Lewis, 2017). In some cases, autistic adults prefer not to disclose their autism diagnosis because they see no benefit in doing so, or fear it may disadvantage them in terms of employment opportunities or financially through higher associated medical costs (Attwood, 2007; Huang et al., 2022; Robison, 2019).

It is understood that having a strong social identity satisfies the human psychological need to belong and promotes self-esteem (Greenaway et al., 2016), and autistic people and community groups increasingly promote a positive reconceptualisation of ASC as a form of difference, or neurodivergence, rather than disability (Happé & Frith, 2020). For some adults who receive an ASC diagnosis in adulthood, diagnosis and positive identification with autism is associated with improved personal self-esteem and a sense of belonging to a collective group (Cooper et al., 2017). For others there are concerns that the perception of others, including GPs and other health professionals, may be framed according to narrow and negative stereotypes (Jones et al., 2014; Treweek et al., 2019). While many adults experience relief upon diagnosis and a sense of greater self-acceptance (Hickey et al., 2018; Smith & Jones, 2020), for a significant number it is upsetting, and relief is accompanied by negative emotions such as anxiety, confusion and anger (Jones et al., 2014). Changes in diagnostic labels, such as the removal from DSM-5 of Asperger disorder, defined in the DSM-IV as a sub-category of autism without cognitive or language delays (American Psychiatric Association, 2000), upset many individuals and communities who identified strongly with Asperger syndrome (AS) and its associations with neurodiversity rather than disability (Rosen et al., 2021). But while some individuals diagnosed in adulthood prefer and strongly identify with the AS label because it is perceived as carrying less stigma and risk of being misunderstood or under-estimated, others report difficulty accepting any diagnosis (Attwood, 2007; Jones et al., 2014). For these individuals and those who experience less acceptance from those around them, such as friends and family, there is a higher prevalence of depression (Cage et al., 2018). Varying responses to and acceptance of an autism diagnosis can also influence post-diagnostic support. For instance, some newly-diagnosed autistic adults who perceive their autistic identity in a positive light are more willing to embrace the peer support of a new (i.e., autistic) community than others for whom acceptance and disclosure is difficult (Crompton et al., 2022).

Despite increasing numbers of adults seeking an autism diagnosis (Happé et al., 2016) our understanding of older adults' pathways to autistic identity and diagnosis is still very formative. Most studies have been conducted in the United Kingdom (Huang et al., 2020), with only a handful examining adults' experiences of diagnosis, disclosure and support in adulthood (Crompton et al., 2022; Griffith et al., 2012; Huang et al., 2022; Leedham et al., 2019; Lilley et al., 2022; Milner et al., 2019; Webster & Garvis, 2016;). Those studies that have specifically investigated diagnosis in adults over the age of fifty have found that participants reported diagnosis was a catalyst for reflecting on their lives and resulted in greater self-acceptance and self-understanding of past (and ongoing) difficulties. However, highlighting the complexity and heterogeneity in autistic experience, whereas some late diagnosed older adults externalised their autism as distinctly separate from their "self" (M_{age} = 60.3 years; Hickey at al., 2018), others attributed a positive transformation to their self-identity, enhanced self-awareness and self-understanding, and a sense of authenticity to their autism diagnosis (M_{age} = 52.89 years; Lilley et al., 2022).

However, even quantifying what constitutes an "older autistic adult" for research purposes is somewhat challenging. Although in geropsychology adults aged 65 to 73 years are classified as "young" old (Notthoff & Gerstorf, 2017), fifty years has been agreed as an arbitrary age threshold for studies on autism and ageing to take account of the potential influences of complex health problems and lower life expectancy associated with autism (Roestorf et al., 2019). While this makes sense given the pre-paradigmatic stage of research in this area, in terms of normative age-graded factors that inform contemporary lifespan perspectives on ageing (Riffin & Löckenhoff, 2017) it means that what is understood about ageing with autism now and at least into the near future may be derived from samples of predominantly middle-aged not older adults. This may make it difficult to identify how, if at all, ageing with autism corresponds with typical age-related changes in a range of domains. It may also influence our understanding of what motivates people to seek an autism diagnosis in later life. By way of example, in one study two older adults' (aged 63 and 74) outlier data points relating to diagnosis and self-rated autistic traits were removed from analyses to reduce skewness (Happé et al., 2016), resulting in more robust results (autism symptoms were rated less severely by the older participants). While this made sense statistically, from the perspective of adaptive ageing within a developmental lifespan framework (Baltes & Carstensen, 2003; Carstensenet al., 1999), this skewness may simply have been a reflection of how older autistic adults' experiences differ quantitatively from those of younger adults – as is the case in typical ageing – because they are motivated by distinctly different social and emotional goals at different stages of life. That is, just as autistic individuals progress through typical developmental life stages such as adolescence and young adulthood, they may also pursue and attain meaningful personal life goals selected and adapted in later life to minimise losses or impairments and maximise gains (Baltes & Baltes, 1990; Baltes & Carstensen, 2003). If this is so, it may influence older adults' motivation for and how they perceive a late-life diagnosis of autism.

Ageing is a heterogenous stage of life (Baltes & Baltes, 1990) and autism is known to be a heterogenous condition (Lord et al., 2020), with experiences differing depending on a range of personal and life factors independent of it (Happé et al., 2016). More research from different socio-cultural perspectives (Huang et al., 2020), and that take into account accepted social constructions of "old age" (Notthoff & Gerstorf, 2017), is needed to broaden our understanding of the impact of receiving a late-life diagnosis on older autistic adults. As will be explored in Chapters 9 and 10, lifespan psychology might also offer a guiding framework for understanding the potential impact of diagnosis later in life.

3.3.2 Emotional Functioning

Emotional functioning is integral to the achievement of meaningful outcomes and enhanced wellbeing in older adults (World Health Organization, 2020). It is also of particular significance to autism. Core symptoms of ASC are associated with impaired emotion regulation and in turn are linked to a range of mental health problems in autistic people (Cai et al., 2018). That mental health issues cause problems in functioning into old age for individuals with ASC, whether in terms of social functioning, quality of life or outcomes, seems likely (Magiati et al., 2014; Mason et al, 2018, Howlin 2021). It is known that co-occurring mental health issues are more prevalent in autistic adults than in the general population (Hollocks et al., 2019), and remain so in later life. A recent study found 46.8% of older autistic individuals had a diagnosis of anxiety disorder and 36.7% had a diagnosis of depression (Bishop-Fitzpatrick & Rubenstein, 2019). However, most of the little that is known about emotional functioning and comorbid mental health problems and their role in adult outcomes is based on research with autistic adults in early to middle-adulthood, not older adults. For instance, a recent systematic review of research investigating social anxiety in ASC identified only one study incorporating older adults (Spain et al., 2018). Similarly, only studies with middle-aged adults were identified in Wigham et al.'s (2017) systematic review examining the rates of depression in individuals with high functioning autism, and Zahid and Upthegrove's (2017) systematic review of suicidality in autism spectrum conditions. According to findings from studies comprising young to middle-aged adults recruited from a mix of clinic and community-based organisations, the most frequent comorbid diagnoses were for mood and anxiety disorders, which were clearly over-represented compared to the general population (Bejerot et al., 2014; Joshi et al., 2013; Maddox & White, 2015; Russell et al., 2016). Alarmingly, individuals with ASC and a comorbid mental illness, particularly depression, anxiety and mood disorders, also seem to be at heightened risk of suicidal ideation and attempts (Cassidy et al., 2018; Lai & Baron-Cohen; 2015; Zahid & Upthegrove, 2017). Suicide and self-harm are among the leading causes of death in individuals with autism, although whether this is also the case for older adults is not well understood (Hwang et al., 2019).

Although recent studies of older autistic adults suggest that mental health problems continue into older adulthood (Roestorf et al., 2022; Uljarević et al., 2019; Yarar et al, 2022) and are accompanied by ongoing negative life experiences (Hickey et al., 2018) and lower quality of life (Mason et al., 2018), they may do so at lower rates than at other life stages in adulthood. For instance, Lever and Geurts (2016) investigated differences in the occurrence of psychiatric disorders across the lifespan in a comparison of three groups of adults with high-functioning autism – young (19 to 38 years), middle-aged (39 to 54 years), and older (55 to 79 years) – as well as with age-matched groups of neurotypical adults. The results revealed that although psychological distress was still higher for older adults with ASC than it was in the typically developing comparison group, psychiatric comorbidities were less prevalent in this group than they were for younger adults with ASC, suggesting that perhaps there is a reduction in psychopathology in later life in older adults with ASC. A similar pattern was identified by Uljarević et al. (2019) in a cross-sectional examination of age trends in self-reported anxiety and depression symptomology across the lifespan in a sample of 255 Australian adults with ASC and ranging in age from older adolescence (age range 15 to 21 years) through to young and middle-adulthood (age ranges 22 to 39 years and 40 to 64 years respectively) and into old age (65 years and older). While both anxiety and depression symptoms were reported by more than one third of participants, with comorbidity reported in more than a quarter of the sample, the authors found there was a slight gradual increase in reported symptomology in both anxiety and depression from adolescence though to a peak in middle-aged adulthood, and then a decline in older adulthood, although there were no significant differences between age groups. The authors found, as did Lever and Geurts' study, that higher symptomology in older adults was predicted by female gender and ASC severity. Nylander and colleagues (2018) also found high rates of comorbid mood and anxiety disorders in the high functioning sub-sample of a large clinic sample (N = 601) of adults with ASCs aged 55 years and older. Although the authors did not examine differences in rates across gender or age range they did report that 63% of individuals with low support needs in the sample had been prescribed anti-psychotic drugs, which they concluded was to manage ASC behaviours given only 12% across the whole sample had a diagnosed psychotic disorder. These studies' findings suggest that prevalence rates for psychopathology, particularly mood and anxiety disorders, in adults with ASC, may decrease in later life, although they remain higher for women than men. This is a pattern reflected in the prevalence rates of mood, anxiety and comorbid disorders in typically developing older adults, including the difference in rates between men and women (Byers et al., 2010; Diehl & Wahl, 2020), and also in older adults with other neurodevelopmental disabilities such as schizophrenia (Jeste et al., 2011).

However, in comparison to the typically developing population, emotional ageing in autistic adults is little understood. For instance it is known that the risk of anxiety or depression or both in older adults in the general population is associated with a number of factors including a neurotic personality profile, a lifetime of chronic stress, experience of a severe life event such as bereavement, loneliness, and social difficulties (Blazer & Hybels, 2005; Bryant et al., 2008; Byers et al, 2010; Charles & Carstensen, 2010). But most research on the risk factors and triggers for mental health problems in autistic adults examines individuals in early and middle-adulthood and is more often focused on the experience and impact of anxiety rather than depression (White et al., 2018). The research, primarily investigations of cross-sectional relationships, is inconsistent (Stringer et al., 2020) although characteristics typically associated with a diagnosis of ASC, such as social and communication difficulties (Müller et al., 2008) and atypical sensory sensitivities and restrictive behaviours linked to intolerance of uncertainty (Hwang et al., 2020) have been identified as factors, as has poor executive functioning (Wallace et al., 2016) and IQ (Stringer et al., 2020). Emotional factors including poor emotion regulation (Mazefsky et al., 2013), often accompanied by alexithymia (South & Rodgers, 2017), rumination (White et al., 2018) and fear of negative evaluation (Maddox & White, 2015) have also been associated with mental health problems as have family characteristics and relational and social problems. These range from loneliness, relationship conflict and low social support (Gotham et al., 2014; Smith & White, 2020) to parental education level (Stringer et al., 2020) and discrimination, unemployment, financial hardship and sexual abuse (Bargiela et al., 2016; Griffiths et al., 2019). Research suggests these factors may be particularly debilitating for autistic individuals who lack a strong self-identity (Attwood & Garnett, 2016), have a poor sense of self-acceptance and perceive a lack of acceptance and respect from those around them (Cage et al., 2018).

There is growing evidence to suggest that autistic adults attempt to ameliorate perceived difference from others by using compensatory strategies, such as camouflaging or masking their autistic characteristics, in social situations including in the workplace (Livingston & Happé, 2017). As discussed in Chapter 2 (see section 2.5), camouflaging strategies motivated by a desire to connect socially result for some in feelings of emotional and mental exhaustion (Hull et al., 2017) and suicidality (Cassidy et al., 2018). For these people camouflaging or masking can also lead to lack of appropriate support because they are perceived to be coping and are therefore not listened to (Cam-Crosbie et al., 2019), are mis-diagnosed, or miss out on a diagnosis altogether (Brugha et al., 2011; Livingston & Happé, 2017). Several qualitative studies have revealed middle-aged autistic adults find the demands of camouflaging compound employment difficulties resulting in stress and anxiety (Griffith et al., 2012; Hickey et al., 2018; Maisel et al., 2016; Robertson et al., 2018).

However, there is also qualitative evidence that some autistic adults adopt potentially more positive, self-initiated coping strategies to cope with stress and anxiety. Some participants have revealed that engagement in spiritual practice, physical activity and solitude are helpful for emotion regulation (Hickey et al., 2018; Müller et al., 2008) while others report using structure and advance planning in daily routines combined with in-the-moment strategies such as breathing techniques, distraction and persevering or avoidance (Robertson et al., 2018). Whether similar triggers and coping strategies are associated with older adults on the spectrum has not been extensively explored. Initial evidence has been gleaned from case studies of elderly adults diagnosed with ASC following late-life presentation for psychiatric assessment as a result of mood or anxiety disorders. Typical later life events, such as the death of a parent or partner, retirement or changes in established routines may trigger late-onset psychiatric problems and subsequent distress and upheaval in their lives (James et al., 2006; van Niekerk et al., 2011), but the coping mechanisms or other factors that enabled these individuals to function in the community for almost a whole lifetime without coming to the attention of health professionals for either autism or mental health problems is not well understood (Happé & Frith, 2020). It seems that while some autistic individuals may be vulnerable to negative life experiences known to be risk factors for mental illness, others are resilient to the adversities and daily challenges associated with autism (Lai & Szatmari, 2019). Resilience garnered through life experience is known to alleviate the effects of stress and adversity, bringing with it greater adaptive functioning and, for some individuals, better than expected outcomes (Rutter, 2012) but whether it may be a protective factor against mental health problems, in the context of autism spectrum conditions, is also not well understood (Szatmari, 2018).

Mental health problems are known to predict poor quality of life in typically developing older adults, and there is evidence that they are predictive of poor outcomes in autistic adults too (McCauley et al., 2020; Scheeren et al., 2022). This is an aspect of ageing in autism about which little is known (Howlin, 2021), although evidence from very recent studies is emerging to fill this gap (Tse et al., 2021). In one such study, Mason and colleagues (2019) examined the impact of mental health difficulties on quality of life in older adults with ASC. Within a sample of older autistic adults with a mean age of 61.5 years these researchers examined the associations between self-reported mental health problems, subjective quality of life (measured according to scores on physical, social, psychological and environmental domains) and participation in normative benchmarks of adult outcomes, such as employment, independent living and social engagement. Mental health issues, particularly depression, were found to be a factor in the lives of a significant proportion of these older autistic adults, and were associated with poor quality of life. However, contrary to expectations, anxiety was not associated with lower quality of life in the social domain. Further, the authors reported that despite the prevalence of mental health difficulties in this sample, approximately 60% of individuals scored a good outcome according to normative measures. The authors noted this unexpected finding was inconsistent with earlier studies of younger autistic adults who had reported less favourable outcome scores on the same measures. Similar patterns were found by Yarar et al. (2022) and Roestorf et al., (2022), with the former group of researchers finding significantly more young adults (M_{age} = 31.03 years) self-reported anxiety than older adults (M_{age} = 57.88 years). Roestorf et al. (2022) did not find a significant difference between younger and older autistic adults (age ranges 31.89 to 36.23 years and 58.61 to 60.94 years respectively) in reported mental health difficulties, but there was a trend towards lower scores in both anxiety and depression for older adults, and both studies also found that mental health problems, particularly depression, were predictive of poor QoL.

Given the relationship between poor mental health and QoL is not well understood, as research on ageing in autism expands understanding the nuances of individual differences might help to address this gap (Roestorf et al., 2022). Although Mason and colleagues included some illustrative quotes from participants to add insight to their results, these were not sufficiently detailed or broad enough to provide a deeper understanding or context to the experiences reported in their findings. The authors concluded that consultation with older autistic adults rather than questionnaire style measures of normative outcomes may be a more appropriate way to identify older adults support needs for optimal quality of life. Indeed, how psychopathology is assessed in autism research may be influenced by whether interviews or questionnaires are used, particularly as the latter may fail to cater for uneven profiles in communication skills, emotional literacy and insight characteristics of autism (Stringer et al., 2020). It is vital that there is a better understanding of the developmental trajectory of emotional functioning in autism and how it is experienced in later life by older autistic adults. An ideographic exploration of changes in mental health over the lifespan may go some way to addressing this gap in the literature.

3.4 Rationale and Aim

As people age, their perception that they have less time left to live motivates them to prioritise emotional over knowledge-related goals. This in turn precipitates a focus on the present and a change in social goals such as a preference for interactions that are familiar, predictable and positive (Carstensen et al., 1999). However, although research on older adults with autism is increasing, researchers have not explored how or if the extensive evidence for successful ageing in the general population might relate to the developmental trajectory of social and emotional functioning of autism across the lifespan and associated outcomes. As this chapter has outlined, anticipated later life outcomes for autistic adults are frequently framed in terms of negative stereotypes of ageing rather than evidence-based gerontological research, and findings have been mixed depending on how outcome and quality of life are defined, what measures are used and the stage of life of participants. Two important factors unique to autism that might impact on successful ageing are late-life diagnosis, and mental health problems. There is a dearth of research on the former, and mixed results from studies on the latter, including some trends that suggest lower levels of mental health problems in older adults are consistent with patterns in normative ageing, although this parallel pattern has not received research attention. Thus, this chapter reveals clear gaps and limitations in the literature that beg addressing. Could it be that just as autistic individuals progress through typical developmental life stages such as adolescence and young adulthood, they also experience characteristic aspects of older adulthood such as the pursuit and attainment of meaningful personal life goals selected and adapted in later life to minimise losses or impairments and maximise gains (Baltes & Baltes, 1990; Baltes & Carstensen, 2003)? If this is so, could these shifts in priorities influence older autistic adults' motivation for, and how they perceive, a late-life diagnosis of autism, and how they regulate their emotions? One of the aims of the current program of research was to seek answers to these questions by exploring qualitatively the personal experiences and perspectives of older autistic adults in relation to changes in mental health and emotional functioning across the lifespan. Another aim was to conduct a theoretical analysis of the relevance of lifespan developmental psychology as a framework for understanding the potential for successful ageing in autism.

3.5 Research Questions and Thesis Aims

In summary, there are glaring gaps in our understanding of ageing in autism. In particular, the developmental trajectory of social and emotional functioning in autism over the lifespan and into later life is still not well understood, and there is very little is known about older autistic adults' everyday outlook on life and the future. For instance, how is autism experienced by older adults? Have they experienced changes in their autistic characteristics or social and emotional functioning throughout life? What coping strategies have they used? What are their experiences and perspectives on ageing? Do they have concerns for the future? By exploring the unique and individual experiences and insights of older autistic adults it is hoped that this research program might go some way to addressing the identified gaps in the literature and make sense of conflicting evidence on ageing in autism, and especially social and emotional outcomes, outlined in Chapters 2 and 3. Another critical limitation of the relatively sparse extant research on autism in later life is its failure to consider ageing from a broader developmental perspective. It is not known if patterns of ageing in the typically developing population are evident in autistic ageing. Insights from gerontological research on successful ageing might provide a useful theoretical framework for understanding ageing in autism that addresses this gap.

Thus, the aim of the current program of research was twofold. The first aim was to explore cognitively able older adults' experiences of ageing with relation to changes in social and emotional functioning over the lifespan and in later life and their concerns for the future. By taking a qualitative approach using semi-structured interviews to gain in depth personal perspectives it is hoped that the insights gained might go some way to better understanding changes over time in social and communication difficulties and mental health, particularly anxiety and depression and coping strategies, in autism as well as older autistic adults' outlook on life, ageing and the future. The second aim was to investigate the applicability of lifespan developmental psychology as a theoretical framework for understanding adaptive change and the potential for successful ageing in autism. It is hoped that by building on both the empirical evidence and our theoretical understanding of ageing in autism this body of work will provide directions for future research and clinical initiatives that are meaningful and targeted towards the unique needs of older autistic adults.

Chapter 4: Methodology

4.1 Methodological Approach

The inductive nature of qualitative analysis lends itself to generating theory, particularly in under-researched areas, while also giving a voice to and providing insight into the experience of excluded or over-looked sub-populations such as older adults on the autism spectrum (Happé & Charlton, 2012; Pistrang & Barker, 2012). A focus on individual differences to identify novel factors in a psychological phenomenon is facilitated by the use of qualitative data because it is one way to determine the meaning of experiences (Rutter, 2012). The results of qualitative analysis may also provide the basis for subsequent quantitative enquiry to verify and generalise those patterns and themes identified, or to illuminate findings from quantitative research (Bölte, 2014). As such, qualitative analysis has been used to better understand individual processes in successful ageing (Reichstadt et al., 2010), and is also an increasingly accepted research methodology to investigate under-researched sub-groups within the autistic population (Bölte, 2014), including older adults (Hickey et al., 2018). Interpretative phenomenological analysis (IPA) is a qualitative methodological approach typically involving populations about which little is known, and is particularly suited to psychological research (Smith et al., 2009).

IPA is especially suitable to autism research (Howard et al., 2019). There is a push for greater inclusiveness and participation of autistic individuals and stakeholders in priority-setting autism research, reflected in the emergence of translational (Pellicano et al., 2014) or *participatory* autism research (Fletcher-Watson et al., 2019). This socio-ethical approach is based on the principle that the inclusion of autistic individuals and autism communities in all stages of research is critical to ensure that it is relevant and will yield benefits (Roche et al., 2021). With its idiographic focus and intensive, in-depth analysis IPA is a qualitative approach increasingly adopted in autism research. It provides meaningful participation for autistic individuals and situates them as the experts on their world and lived experience and embraces them as equal partners in the research process, which goes some way to addressing the double empathy problem often associated with mis-matched exchanges between researcher and autistic participant (Howard et al., 2019; Milton, 2012). Further, as a robust analytical methodology, IPA also serves as a valid alternative or adjunct to quantitative methods such as randomised controlled trials which are traditionally viewed as the 'gold standard' but are perceived by some in the autistic community as discounting or ignoring the value of autistic subjective experiences of and to research aimed at accommodating the needs of those on the autism spectrum (MacLeod, 2019; Milton, 2012). IPA findings are not intended to be generalisable to the whole autistic population (Howard et al., 2019) but rather serve the vital goal of gaining real life perspectives on issues that are important to autistic people (Lord et al., 2020) and enhancing our understanding of how autism is experienced (Howard et al., 2019).

There is a strong evidence-base for the use of IPA in autism research (MacLeod, 2019). In particular, IPA has been used to inform our understanding of autism across the lifespan through exploration of a range of autistic experiences from autistic adolescents' perceptions of diagnosis and disclosure (Huws & Jones, 2008) and transition to emerging adulthood (Mattys et al., 2018), to autistic adults' views on stereotypes (Treweek et al., 2018) and the meaning of childhood adversity and resilience (Heselton et al., 2022). Thus, IPA was identified as an appropriate qualitative methodology for this program of research with independently functioning older adults and their experiences of changes in autistic characteristics and social-emotional functioning over the lifespan.

A key underpinning of IPA methodology is to better understand others' relationship to the world. Specifically, it provides a psychological experiential methodology (Smith, 2017) for the analysis and interpretation of how people who share a particular experience or condition make sense of the world around them, both cognitively and from an affective perspective. The theoretical principles of this method require a "bottom-up" analytical approach which allows for an intensive and in-depth exploration and interpretation of an individual's first-hand, or "lived", experience of a particular phenomenon, and provides insight into how they make sense of the world around them (Smith et al., 2009). IPA involves a double hermeneutic approach whereby the researcher, through a process of engagement and interpretation, attempts to makes sense of these experiences (Smith, 2011). Inherent to IPA's double hermeneutic approach is that the analysis is the researcher's *interpretation* of the participant's experiences, not a claim of *objective fact*. This is an important distinction in the context of autism research as it is acknowledgement that what is described is interpreted through a non-autistic lens, but is nonetheless a co-creation of the meaning of experiences shared by the participant (Heselton et al., 2021). In particular, IPA's idiographic approach means that although patterns and themes are identified and across the corpus, how they have manifested individually in the experiences of each of the participants is investigated and analysed. The particular nuances and uniquely individual details of each case are actively retained and integrated to inform an analysis that highlights the convergence and divergence of experiences within the project's sample (Smith & Shinebourne, 2012). The overarching purpose of this style of analysis is to mine for rich and subjective detail of participants' experiences from which broader patterns and themes may be identified, rather than to impose a theoretical framework or hypothesis from the outset.

IPA lends itself to a purposively selected homogenous sample for whom the research question has meaning and relevance (Smith et al., 2009). The methodological approach of IPA, and its idiographic focus on intensive, indepth analysis, means it is better suited to a smaller sample size, typically ranging from one to six, with a sample of three considered optimal. A smaller sample size also minimises the risk of losing some of the rich detail this type of qualitative research promises due to the time constraints of conducting and analysing a large number of sometimes lengthy interviews. Further, using a smaller sample strengthens the analysis in that it allows the researcher to recall and reflect on individual accounts, which may reduce the possibility of losing any subtle similarities or differences between cases, and ensures a more nuanced identification of patterns and themes. Finding participants who meet the very narrow and specific criteria of the current research program, particularly the requirement of a formal ASC diagnosis (which is, in itself, a function of the particular experience of these individuals in the Australian context, and an issue requiring further investigation) is difficult. This is an issue experienced by other researchers, and has resulted in study sample age criteria being lowered due to the difficulty of recruiting older age participants (see Griffith et al., 2012). Therefore, using a methodology such as IPA that requires a smaller sample size not only allows for exploration of and nuanced insight into the experiences of an under-researched sub-group within the autism community, it also helps to resolve, in the short term, the challenge of finding a large sample of participants who meet this research program's inclusion criteria.

Ensuring the quality, validity and reliability of qualitative analyses is vital to the research process. Although respondent validation is an increasingly required check for validity and reliability generally in qualitative research, and in particular in autism research, this is not an appropriate validation strategy for IPA which, by its very nature, is interpretative. IPA's analytical process – the double hermeneutic – involves an amalgamation of individual accounts, researcher interpretation and the elapse of time, all of which respondent validation would render counter-productive (Larkin & Thompson, 2011). Seeking respondent feedback on the interpretative analysis of their interview transcripts, and refining the analysis on the basis of that feedback is not necessary in IPA as the participant is already positioned as the "expert". Indeed, this is one of the advantages of IPA in autism research (Howard et al., 2019). Further, seeking respondent feedback might suggest that participants have been attributed privileged status in the analysis: that their feedback is direct validation or refutation of the researcher's analytic interpretation rather than another source of data and insight in themselves ripe for analysis (Silverman, 2005) and this would be contrary to one of the integral aspects of IPA. Sample validation (that is, validation by an individual who was eligible to participate in the research but didn't) or independent audit are alternative validity checks which are more appropriate to IPA (Larkin & Thompson, 2011; Smith et al., 2009). A diagrammatic or tabular summary of the interpretative process, which sets out clearly a breakdown of the analysis behind each theme as well as the recurrence of themes across individual cases within the larger corpus, provides an appropriate and coherent audit trail of the analytic process to ensure and enhance the validity of findings derived through IPA methodology (Smith et al., 2009).

Thus, IPA lends itself to exploratory research questions involving populations about which little is known, such as older adults with ASCs. Accordingly, for this project, informant data was collected from semi-structured interviews and analysed using IPA methodology.

4.2 Ethical Clearance

This research project was cleared in accordance with the ethical review processes of the University of Queensland and within the guidelines of Australia's National Statement on Ethical Conduct in Human Research. The Ethics approval number is 16-PSYCH-PHD-29-JS.

4.3 Participants

Participants in this research were aged 50 years or over and had a diagnosis of Autism Spectrum Disorder, Level 1 (referred to here as HFA) or Asperger's syndrome (AS). Because having a formal diagnosis of Autism Spectrum Disorder, Level 1 is less common in adults, particularly older adults, than it is in children (Baxter et. al. 2015) initially individuals who enquired about the project were accepted if they self-identified as having AS or being at the high-functioning end of the Autism Spectrum but didn't have a formal diagnosis. The initial rationale for this less rigorous diagnostic requirement was that the current project was conceived in the first place as an exploratory investigation of a sub-group of the autistic population that has been under-identified – hence under-diagnosed – and under-researched (Happé et. al., 2016; Lai & Baron-Cohen, 2015). Accordingly, the adult self-report version of the Social Responsiveness Scale (SRS-2; Constantino & Gruber, 2012), a screening measure for social responsiveness and ASD characteristics was used as a screening check for all participants.

However, although research investigating autism in adult populations is relatively new, it has evolved rapidly during the course of the current program of research. Within twelve months of data collection, it was observed that there was a marked tightening of the criteria stipulated by journals publishing autism research, such that studies investigating ASC in adults were more stringently required to comprise participants with a formal diagnosis of ASC. Requirements for diagnostic confirmation in autism research continued to evolve and sometime later participants' diagnostic status depended on the goals of the study in which they were participating; it was deemed acceptable for ascertainment methods to accommodate a range of diagnostic profiles according to the autistic characteristics or service requirements under investigation (Bal & Lounds Taylor, 2019). Although there is not yet an internationally agreed gold-standard diagnostic tool for adults, diagnostic interview by a trained clinical psychologist is an appropriate method of diagnosis (Fusar-Poli et al., 2017; Bal & Lounds Taylor, 2019). Therefore, it was deemed that expanding the current research program to include a diagnostic interview with consenting participants would serve to strengthen its methodology and enhance the prospect of its findings being published, thus meeting the aim of contributing to the expanding field of autism research relating to older adults. Accordingly, participants in this program of work who identified as having a high-functioning autism spectrum condition, but who did not have a formal diagnosis, were invited to participate in a second follow-up interview with an experienced clinical psychologist, to undergo a formal diagnostic assessment. Participation in this follow-up interview was voluntary. All procedures relating to voluntary withdrawal, ensuring anonymity and confidentiality of the data gathered, and the debriefing of participants complied with the original Ethical Review Application for the project.

Of the four participants invited to take part in the additional diagnostic interview all agreed except one. The declining participant was female, aged 69 years, and scored in the moderate range of the SRS-2 self-report screening measure. Her initial involvement in the project was motivated by a desire to learn more about ASC, but also in the hope that further research would benefit three of her grandchildren who have formal diagnoses of ASC. She had previously, with the support of family, participated in a formal diagnostic process at a local clinic specialising in autism spectrum disorders, but did not attend the final appointment due to her ambivalence about the personal ramifications of meeting the diagnostic criteria. She was regretful that her experiences could not be included in the analysis, but again found the possibility of meeting the criteria herself disturbing and potentially a threat to her sense of self. This participant's interview data had already been analysed and, with the exception of some aspects of her attitude to and experience of diagnosis, was consistent with the themes identified in the analyses. Therefore, in the context of the issues of older adult diagnosis raised above, and given the unique perspective of this participant's experience of diagnosis and other life matters as an older female with strong ASC characteristics, her data was not excluded from the final results. The remaining three participants met the diagnostic criteria for Autism Spectrum Disorder, Level 1.

The concept and definition of old age varies, even amongst ageing researchers. However, age stratification typically continues to be understood according to chronological age, with "young old" referring to those aged approximately 65 to 74; "middle old" to those aged approximately 75 to 84 years; and "old old" referring to individuals aged over 85 years (Notthoff & Gerstorf, 2017). By this classification of old age, participation in this research project would be restricted to individuals aged at least 65 years old. However, to compensate for the additional significant difficulty, as outlined above, of finding eligible participants who met both the 65 years age criteria as well as the diagnostic criteria, individuals aged 50 and over were eligible to participate.

Therefore, the age range of the ten participants in this research project was 53 to 74 years (*M* = 63.30; *SD* = 7.70). Within this range, there was a cluster of six participants in the "young old" category (aged 66 to 74 years), and the remaining four were in a younger cluster ranging from 53 to 58 years. Six of the participants were male, and four were female. All participants were based in South-East Queensland, Australia except for one female in regional Victoria and another in Norway. Participant characteristics are set out in Table 1.

Table 1

Demographic Details of Participants

Participant ID[a]	Gender	Age	Diagnosis	Age at Diagnosis[d]	Relationship Status	Living Status	Employment	Education Level	Mental Health (Self-report)	Medication	Therapy (formal and informal)
John	M	74	Self – "mild Asperger's"[b; c]	59	Married	With spouse	Retired / volunteer work	Bachelor's degree	Depression Anxiety	Anti-depressants previously; none currently	Physical activity: gardening
Doug	M	69	Self – "Aspie"[b; c]	~63	Married	With spouse	Retired	Bachelor's degree	Stress	None currently	ASC Couples therapy
Anne	F	69	Formal ASD/ Self – "Aspie"[c]	54	Married	With spouse	Retired	Diploma Ed.	Depression Anxiety	Anti-depressants current	
Charles	M	67	Self – Autistic[b]	59	Divorced	Supported housing	Retired	Senior school certificate	Suicide attempts Extended hospitalisation	Lithium Risperidone	Music Nature
Ken	M	66	Self – "Aspie"[b; c]	65	Married	With spouse	Retired	Bachelor's degree	Low mood	No	ASC Couples therapy Running, Walking, Surfing, Meditation

Participant ID[a]	Gender	Age	Diagnosis	Age at Diagnosis[d]	Relationship Status	Living Status	Employment	Education Level	Mental Health (Self-report)	Medication	Therapy (formal and informal)
Rose	F	57	Formal – ASD	52	Single	Independent with part-time support	Part-time work	Bachelor's degree	Depression Anxiety	Previously anti-depressants and anti-anxiety	Individual and group therapy Mindfulness, Massage, Swimming
Jane	F	55	Formal – ASD/ Self – "Aspie"[c]	54	Married	With spouse	Retired / volunteer work	Bachelor's degree	Low mood	No	Swimming
Anthony	M	54	Formal – ASD/ Self – "Aspie"[c]	45	Married	With spouse	Full-time	Bachelor's degree	Grief	No	ASC Couples therapy
Paul	M	53	Formal – ASD	44	Single	Independent	Full-time	PhD	Depression Anxiety	Previously anti-depressants and anti-anxiety	Gardening
Margaret	F	69	Self – AS[c; e]	~68-9	Divorced	Independent	Retired / volunteer work	Bachelor's degree	Depression	No	Walking

[a] Participants' names have been changed to preserve anonymity. Specific data on participants' ethnicity and socioeconomic status was not recorded.

[b] Diagnostic assessment of Autism Spectrum Disorder, Level 1 during the current research program.

[c] Preference for the term "Asperger's Syndrome" or "Aspie" rather than ASC and self-identifies as such.

[d] Refers to age at time of self-diagnosis or first self-identification with AS/ASC.

[e] Declined clinical diagnostic assessment.

4.4 Materials

4.4.1 Diagnostic Interview Schedule

A clinician interview schedule using DSM-5 criteria (American Psychiatric Association, 2013) and developed by Professor Tony Attwood to aid in the diagnosis of autism spectrum conditions in adults in a clinic setting was used to diagnose participants in the project who identified as having an autism spectrum condition but did not have a formal clinical diagnosis.

4.4.2 Social Responsiveness Scale-2

The Social Responsiveness Scale (2nd Edition) Adult Self-Report Form (SRS-2; Constantino & Gruber, 2012) was used as an additional ASC screening measure. The SRS-2 adult self-report form is an autism assessment tool developed to identify social impairment associated with ASCs in individuals aged 19 years and over. The 65-item rating scale asks respondents to rate, from 1 ("not true") to 4 ("almost always true"), their behaviour over the past 6 months across five domains: social awareness (e.g., "I sometimes make the mistake of walking between two people who are trying to talk to one another"); social cognition (e.g., "I do not recognise when others are trying to take advantage of me"); social communication (e.g., "I get frustrated trying to get ideas across in conversations"); social motivation (e.g., "I avoid starting social interactions with other adults"); and repetitive and restricted behaviours (e.g., "I have more difficulty than others with changes in my routine"). A total score above 60 indicates clinically significant impairments in reciprocal social behavior that may interfere with everyday social functioning. The SRS-2 is deemed suitable for research with verbally fluent adults (Lord et al., 2018). There is a strong evidence base for the validity and reliability of this tool for screening adults in ASD research and across cultures, nationalities and clinical groups (Bölte, 2012; Brugha et al., 2015; Takei et al., 2014), with SRS-2 factors demonstrating a high correlation with autism characteristics and behavioural measures (Chan et al., 2017). It is increasingly used as a measure of individual difference in autism research (Happé & Frith, 2020) and is particularly useful in adult research investigating the social domain (Roestorf et al., 2019). The SRS-2 has been used in many other adult research studies as both a screening measure and an outcome measure (Bemmer et al., 2021; Kandalaft & DeBrabander, 2021; Mason et al., 2018; McConachie et al., 2018; Walsh et al., 2019), and with older adults (Geurts & Vissers, 2012; Roestorf et al., 2022; Yarar et al., 2022). SRS-2 results are set out in Table 2.

Table 2

Standardised SRS-2 Scores Based on Participants' Self-Report

Assessment subscale	Participant									
	John	Doug	Anne	Margaret	Charles	Ken	Rose	Jane	Anthony	Paul
Social Awareness	47	81	61	61	64	55	81	52	64	69
Social Cognition	55	76	77	79	51	53	69	65	56	72
Social Communication	52	86	74	63	61	53	78	52	57	75
Social Motivation	52	61	76	71	67	59	66	74	46	82
Social Communication and Interaction (SCI)	52	80	75	70	62	55	76	61	56	78
Restricted Interests and Repetitive Behaviour (RRB)	62	88	82	60	57	55	78	65	78	80
Total Score	54[a]	82	77	68[b]	61	55[a]	77	62	60	79

[a] This participant received a formal clinical diagnosis with an experienced clinical psychologist during the current research program. Although speculative, a total score below the clinical threshold of this self-report assessment tool could be indicative of learned social behaviours and understanding gained over the lifespan by older adults, or a lack of insight.

[b] This participant declined to undergo a formal diagnostic assessment, however a total score above 60 indicates clinically significant impairments in reciprocal social behaviour consistent with an autism spectrum disorder.

4.4.3 Semi-Structured Interview

An open-ended semi-structured interview schedule was developed specifically for the current research project to allow for greater flexibility and coverage of individually relevant topics and issues as they arose within the broader interview framework. Questions were designed to explore participants' perspectives on ASC, their experiences in terms of socio-emotional and behavioural functioning, anxiety and mood disorders, improvements or decline over time in these areas of functioning and autistic characteristics, and thoughts on the future. See Appendix B. for the full interview schedule.

4.5 Procedure

Prior to the project older adults with ASC, and their partners and carers, gathered at a monthly Asperger's community support group meeting, led by Professor Tony Attwood, to discuss informally their experiences and observations of the ageing process. In line with the concept of participatory autism research (Fletcher-Watson et. al., 2019), which advocates for the meaningful involvement of autistic individuals in all aspects of autism research, a key aim of the session was to explore the research priorities of older adults on the autism spectrum particularly with respect to which, if any, factors had helped them reach older adulthood reasonably happily and successfully, and which had proved challenging. In particular, dimensions of functioning for adults aged between 50 and 65 years, and those aged 65 and over, were discussed in terms of DSM-5 diagnostic criteria, cognitive abilities, problem solving, emotions, and medical issues. Each of these categories was addressed in turn, first with a show of hands indicating whether people felt the feature in question had worsened over time, remained stable, or improved, which was recorded in a table on a white board by Tony Attwood, and then followed by a discussion. It was clear throughout the meeting that attendees were keen to share their perspectives and insights, and were strongly encouraging of future research addressing their experiences and needs, particularly those raised as being of importance throughout the workshop.

These insights guided development of the semi-structured interview schedule for the current project. Questions in the interview schedule were designed to explore participants' autistic characteristics and social and emotional functioning over the lifespan, with particular focus on changes in characteristics, and the experience of anxiety and depression. However, in keeping with the inductive approach of IPA methodology, interview questions were open-ended and included prompts to allow for flexibility to reflect on and probe responses to fully explore issues and topics specific to each participant's individual experiences as they were revealed (Smith & Shinebourne, 2012). The interview schedule included questions on ASC identity; changes in ASC characteristics over time; social interaction; coping, worry, stress, anxiety and depression; life reflection and thoughts on the future.

Participants were recruited via local and online autism community groups, including Autism Queensland and Professor Tony Attwood's website, which is a guide and autism-related networking site for parents, professionals, and people with ASC and their partners. Recruitment flyers providing details of the project and how to be involved were also placed in the Minds and Hearts Psychology Clinic for Autism Spectrum Conditions in West End, Brisbane, and Tony Attwood's private clinic in Petrie, north of Brisbane, Queensland.

Potential participants were invited to read a detailed information sheet about the research project before providing written consent to participate. The information sheet outlined the purpose of the research, eligibility criteria (individuals were required to be aged 50 years and over and have a diagnosis of Autism Spectrum Disorder, Level 1), what involvement would require and how to volunteer. Specific information was provided about what participation involved, potential risks, confidentiality and security of data, and ethics clearance and contacts. The information sheet also emphasised that participation was completely voluntary, and participants could choose not to answer particular questions or withdraw from the interview at any point in time. Upon completion of the consent form, which re-stated participants' rights to withdraw at any time as well as details about the confidentiality of the research, participants were contacted to arrange a convenient format, time and place for the interview. Interviews were conducted either face-to-face, by Skype, telephone or email depending on participants' preferences or needs. Of the ten participants, three opted to be interviewed via Skype because they resided outside Brisbane, Queensland. Of the three Skype interviews, one took place over two sessions to accommodate the participant's work commitments. Interviews were conducted by the PhD candidate. The length of interviews was determined by participants' responses and ranged from approximately 48 minutes to two hours and 46 minutes (M = 2h 01m 50s).

At the commencement of each interview session the purpose of the research project was explained again and details about the format and focus of the interview were explained, including participants' rights to withdraw at any time or request breaks. Although the interview schedule was flexibly structured to incorporate breaks as required, none were taken. It was explained that the interview would be audio-recorded, and that participant confidentiality protocols set out in the information sheet would be observed. A written copy of the information sheet was also provided for reference. Verbal consent was then sought for the interview to commence. As outlined in the information sheet, participants then completed the adult form of the SRS-2. Brief instructions about how to fill in the self-report questionnaire were given, and clarification was provided as required. Upon completion of the SRS-2 the interview commenced according to the interview schedule. The interview schedule was broadly followed, but in keeping with the inductive approach of IPA, the interviewer frequently probed for meaning or asked for more detail from the participant (e.g., "I just want to clarify …") to gain a deeper and more insightful sense of the participant's experience of autism. Some of the participants were inclined to digress into lengthy monologues about topics of special interest. In these situations, the interviewer listened for a while – digressions in themselves were a rich source of information about the participants' perspective and experiences – and then drew the participant back to the topic from which they digressed or to the next item on the interview schedule or (e.g., "Now, I'm going to change topics slightly…"). Communication with cognitively able autistic adults via email has been identified as another rich source of data, and allows these individuals an opportunity to reflect on and share their perspective on issues at a pace and manner which is potentially less stressful (Benford & Standen, 2011). Therefore, at the end of each interview, participants were invited to contact the interviewer by email should they wish to share further thoughts or comments on the topics covered after a period of reflection. Additional data via email was received from seven of the ten participants.

Interviews were audiotaped and transcribed verbatim. Data collected via email was added to the end of the interview transcripts for inclusion in the analysis. Transcripts were formatted in Microsoft Word with 5.08cm left and right margins to allow space for notes and commentary on the data. Lines in each transcript were numbered to facilitate transparency in locating key words and extracts from the data. Initial exploratory comments were made in the left margin and emerging themes were noted in the right margin. Identified themes and supporting extracts from the transcript were copied to an analytical table for organisation and further analysis. Data from the interviews was then analysed for patterns and themes in terms of lived experiences relating to changes in autism characteristics and social and emotional functioning over the participants' lifespan.

4.5.1 Qualitative Analysis

Informant data, in the form of hard-copy transcripts, was analysed case-by-case rather than concurrently using IPA as prescribed by Smith, Flower and Larkin's (2009) iterative and inductive cycle of six steps. For each transcript, the first step of the analysis involved immersion in the original data through a process of reading and re-reading the interview transcript, and listening to the audio-recording of the data to fully engage with the participant's "voice" and story. This stage was followed by the second step, a phase of note-taking in the left-hand margin of the transcript which comprised exploratory notes and comments on aspects of the data that were considered to be of potential significance. In particular, descriptive comments relating to objects of concern, such as relationships, events, values or experiences, were identified and noted, as were idiosyncratic linguistic expressions, style of language, and emotional responses, such as laughter or tears. At this stage of the analysis abstract or psychological concepts, which made sense of the patterns of meaning within the individual's account, were also noted. The third step involved identification and development of emergent themes and the connections between them, which were noted in the right-hand column of the transcript. At this point emerging themes and discrete extracts of the transcript were transferred into a new document in chronological order. In the fourth step of the analysis emergent themes were clustered together according to similarities and given a label. This was an iterative process and the themes identified reflected each of the participant's original thoughts and words as well as the researcher's interpretation, thereby encompassing and balancing both the phenomenological (descriptive) process and the interpretative aspect of IPA methodology. At this stage of analysis some themes were subsumed into others or discarded, and compiled in table format with relevant extracts and their line numbers from the data (to enhance transparency), and commentary to contextualise and explain the themes identified. The fifth step of the analysis was a repeat of steps one to four for each transcript. Each transcript was treated independently and ideographically (individually). However, all transcripts and their analyses become part of the hermeneutic circle of understanding that underpins IPA methodology, therefore throughout the analysis there was a cycle whereby the analysis of each new transcript revealed new themes or variations on already-identified themes which in turn influenced the refinement of earlier analyses and emergent themes. A process of analytic induction (Silverman, 2014) was used to accommodate the size of the corpus and also to account for divergent sub-themes identified in individual cases. Accordingly, steps one to four were applied initially to four transcripts to identify sub-themes through intensive analysis of a small amount of data. These themes were then tested through extensive analysis of the remaining data set with a view to finding divergent cases. Divergent cases were accommodated through a process of interrogating and interpreting the relationships between convergent and divergent sub-themes in a way that accounted for the patterns of both similarity and heterogeneity in participants' individual experiences. In this way identification of divergent cases assisted in the analysis as it ensured all exceptions were accommodated through the refinement of themes until all the data fit. Finally, in the sixth step, patterns across the entire corpus were identified. The corpus of this research project was large by IPA standards (both in sample size and hours of transcribed interviews), therefore emphasis in the analyses was placed on identifying key emergent themes at an individual level, with patterns and connections identified at the group level by considering the group of ten cases as a whole rather than each case individually (Smith et al., 2009). Themes were finalised through a process of comparison, reconfiguration, relabelling, and omission that culminated in an audit table. In this final stage of the analysis, the audit table was organised in nests of major themes that included sub-themes, examples from the range of cases, recurrence of themes across the data set, cross-references to the original transcripts and explanatory notes and thus provided a coherent breakdown of the analysis behind each major theme. Throughout the analytic process, a researcher's diary was maintained to maintain methodological rigor and transparency. At the end of each interview, and throughout the analyses, the diary was used to record brief reflections and to provide prompts and background to facilitate the identification and development of themes.

To further ensure methodological rigour and enhance the project's validity a number of other measures were taken. Firstly, each group level theme was required to be supported by individual example extracts from at least five participants' transcripts, and the recurrence of themes across the corpus were tallied and recorded in the audit table as a measure of each theme's prevalence. Secondly, an independent audit of the analysis was performed. This comprised independent analysis of four transcripts according to the procedures outlined in steps one to four above to check the methodological process was logical. A review of the audit table was also conducted to ensure the major themes and sub-themes identified represented a credible interpretation of the data. Interpretation is fundamental to the meaning-making process in IPA but by its very nature it is subjective. Researcher reflexivity is recommended in qualitative research to enhance methodological rigour and transparency (Yardley, 2000). Acknowledgement of the researcher's own lived experiences and assumptions, and reflections on factors that may have influenced the interview process and data analyses, is considered important to the trustworthiness and validity of qualitative autism research (Howard et al., 2019; MacLeod, 2019). For these reasons the author provides a reflexivity disclosure below.

Finally, in keeping with the participatory approach of this program of research, the independent audit and review were undertaken by an autistic research assistant. This additional autistic collaboration provided an invaluable "neurodiverse check" on both the transparency of the analytic process, and the credibility of the analyses, and was another measure taken to ensure the research project was as consistent as possible, within the dictates of IPA methodology, with a participatory approach to autism research (Heselton et al., 2021).

4.5.2 Preserving Validity of the Results in Reporting

A wealth of detailed data was collected and analysed for this research program, resulting in four overarching superordinate themes each with a varying number of underlying sub-themes. To ensure vital participant data and associated analyses are not sacrificed in the service of strict word limits (as qualitative research reports frequently are required to be for publication in medical and health journals (Braun & Clarke, 2019) each theme is reported as a stand-alone chapter. This approach is crucial not only for ensuring the validity of this research program but also so that the results are truly representative of and faithful to the data which in qualitative research is the participants' "voice" represented by data extracts (Braun & Clarke, 2019). Summarising this data in tabular format and according to frequency counts is sometimes recommended as it is more consistent with quantitative research that deals in numerical data typically associated with medical and health research. However, reducing participant perspectives to numbers in this way fails to capture the nuance and detail that recommends qualitative research methods such as IPA in the first place. The adopted structure for reporting themes as chapters is also consistent with IPA methodology that recommends that, in instances where there is an abundance of data, discrete sections of the analyses be reported separately to ensure the reported results and discussion are adequately comprehensive and faithful to the data (Smith et al., 2009). As such, each of the subsequent chapters in Part II will present the data analysis and interpretation of a standalone theme and its sub-themes followed by a summary of conclusions.

4.5.3 Researcher Reflexivity

As the parent of a young man with autism I have a dual perspective on the research in which I have been engaged. My experiences, insights and perspectives as a close family member of an autistic person will necessarily influence my research from the design phase through to the conduct of interviews, data analysis and interpretation. It also means that technically, I also contribute to the participatory nature of my research project.

I am deeply concerned by how much we still do not know about the developmental trajectory of autism, by the lack of public awareness and understanding, the stigma, the social exclusion, the loneliness, the high levels of mental health problems, suicidality – all aspects of autistic experience that our family has experienced. These concerns undoubtedly motivated my research. My son has wonderful talents but there are also vulnerabilities. A constant worry for me, as a parent of an autistic adult, is what will happen to him when I am no longer here to care for him and look out for him. What will happen to him when he grows old?

I made it very clear to all participants in my research project at the outset of each interview that I was a PhD student and did not have clinical experience or qualifications. While it was clear to them that I was an older (mature-aged) student, only in a couple of instances, either in introduction or farewelling, did I refer to being a parent. I did not disclose my personal experience of autism for two reasons. Firstly, I did not wish for the focus of the interview to be turned away from participants' unique experiences and onto mine. Secondly, my son is ambivalent about his autistic diagnosis and prefers that he has control over to whom it is disclosed, and I respect this preference.

Perhaps because I am accustomed to and have my own life experience of some of the unique social and communication behaviours of autism, I felt I was able to quickly establish a connection with the participants in this program of research, and that I was able to form a warm and empathetic participant-researcher relationship. I believe the participants trusted me. Some disclosed thoughts and feelings to me – voluntarily – that they told me they had never shared with anyone else. In a couple of interviews my sense was that for the participant the session was cathartic, almost therapeutic. Many participants told me as much. Some noted that nobody had ever asked them before about what it was like to be autistic, or about their lives. They said it felt good to be able to just talk and say what was on their mind.

All interviewees expressed how important they thought the investigation of ageing and autism is, and all expressed – warmly and sincerely – their gratitude for the time and effort I had taken to sit with them and hear their stories. Really, as I made clear to them, the thanks and gratitude were due to them for being so generous and open, and for sharing the intimacies and intricacies of their lives. For many, delving back into their past was at times painful and there were tears. At other times, and often, there was amused self-deprecation and laughter. Overall, the tone of each interview was astonishingly positive and hopeful. I hadn't expected that; my reading of the literature, and my own fears and concerns for my son, had not prepared me for that experience. It was the biggest surprise of my research and, even before I had analysed the data, I knew that I had at least one unexpected finding. Despite everything they had endured in their lives, astonishingly, the older adults I interviewed expressed a remarkable resilience and positivity about life.

I believe the promotion of participatory research is a necessary development in autism, and is vitally important for all the reasons we have read about in the literature but know intuitively, in any case, as engaged researchers in this area. As I reflect on my own research, and my dual role as researcher and parent to an autistic person, I have experienced first-hand the benefits of this. I know the investigation of ageing and autism is meaningful and of real concern to autistic people and their families because I am one of them.

Through my son I was able to meet and work with my supervisors, Kate Sofronoff and Tony Attwood. Their clinical work and my experience as a parent client and participant in autism research at UQ meant we had multiple overlapping perspectives, experiences, and insights, some from the same side and some from opposite sides of the clinical "fence". Through Tony I had access to older autistic community members who supported and promoted my research because, as Tony's colleague, they trusted me. I believe this benefited the development and design of my research immeasurably. In turn, I was able to trust Kate and Tony. It was invaluable to me, personally and academically, to have a safe place to test ideas and theories and clarify the line between parent and researcher. This last point is perhaps the red flag I wish to raise about participatory research. While it is important, liberating, vindicating, satisfying, even exhilarating at times, to be involved at the frontline of autism research as a parent (and I imagine this must be the case for many autistic individuals and other close family members and friends), at times it can be deeply emotionally distressing and confronting. "Autism" can become so all-consuming that "real life" becomes distorted or even disappears. Most of the autism literature is grim reading when you are the one (or the loved one or "support") it is written about. It has taken me a long time to complete this thesis and submit it. That is mostly because, realistically, the timing was bad – having four teenage boys and a husband who frequently travels away from home does not leave much headspace for research, particularly when one of the boys needs extra time and attention. But as this is a reflection, I must be honest with myself: I know there have been periods of time when my work – thinking and reading and writing about some of the less positive outcomes autistic people experience – was just too confronting and I could not face it as a dispassionate and objective researcher or psychological scientist.

Undoubtedly there have been factors that have influenced my interpretation and analysis of the autism research I have read and my research data. These include conversations with my third supervisor, Nancy Pachana, about the work of Laura Carstensen and Paul and Margaret Baltes; my personal situation and the logistical and emotional implications of living with and supporting our autistic son while also investigating the developmental trajectory of the condition; and concerns relating to my perception of increasing socio-political and ideological preoccupations in autism research that distract from what, as a parent of an autistic person making their way through adulthood, I believe are more pressing scientific and psychological questions. For all that, with the guidance of my supervisors and adherence to a clear and structured methodology, I believe the results of my research are valid, extend our understanding of autism from a lifespan perspective, and propose new ideas for future investigations of the developmental trajectory of autism with particular focus on social and emotional functioning in older autistic adults.

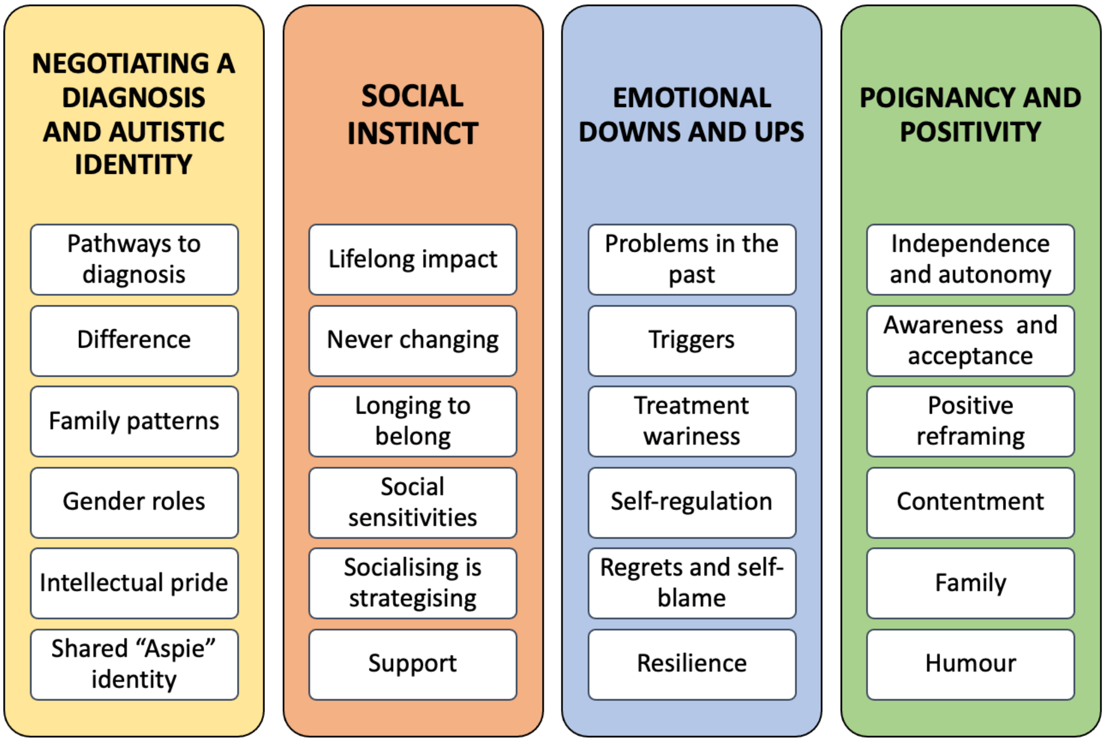
PART II: THE PRESENT

***"I can look back now and sort of cut myself a bit of slack"* – Anne, 69 years**

This section presents the thematic results from the project's interview data analyses. There were four overarching themes: negotiating diagnosis and an autistic identity; social instinct; emotional downs and ups; and poignancy and positivity. Each chapter in this section presents a theme, its sub-themes, interpretations, and discussion. Themes and underlying sub-themes are presented diagrammatically in Figure 1.

Figure 1

Themes and Sub-themes from Participant Interviews



Chapter 5: Negotiating Diagnosis and an Autistic Identity in Later Life

"How does this re-frame what my life looks like?" **– Jane, 55 years**

This chapter reports on the overarching theme of *negotiating diagnosis and an autistic identity in later life*. It presents the unfolding accounts of participants' journeys across the lifespan culminating in making sense of and integrating, as older adults, an autistic self-identity and – in some cases – diagnosis. Sub-themes elaborate on the similarities and differences in each individual's *pathway to diagnosis*. Pathways and responses to autistic identity and diagnosis, and how these were accepted and integrated into their lives, differed according to whether participants were young old or middle aged. The complexities underlying participants' different pathways were framed within the context of sub-themes relating to a lifelong sense of *difference*, *family patterns*, *gender roles*, and *intellectual pride*. These perspectives informed participants' discovery of and identification with a *shared "Aspie" identity*. These sub-themes are presented in Table 3.

Table 3

Negotiating Diagnosis and an Autistic Identity in Later Life Sub-Themes and Illustrative Quotes

Sub-theme	Illustrative Quote
Pathways to diagnosis acceptance	*It hurt, but it's also made sense*
Difference	*A unique difference*
Family patterns	*So maybe it's in the family*
Gender roles	*You know now it's so different with a woman, isn't it?*
Intellectual pride	*I think I'm very intelligent*
Shared "Aspie" identity	*'Cos we're similar Aspie sort of people*

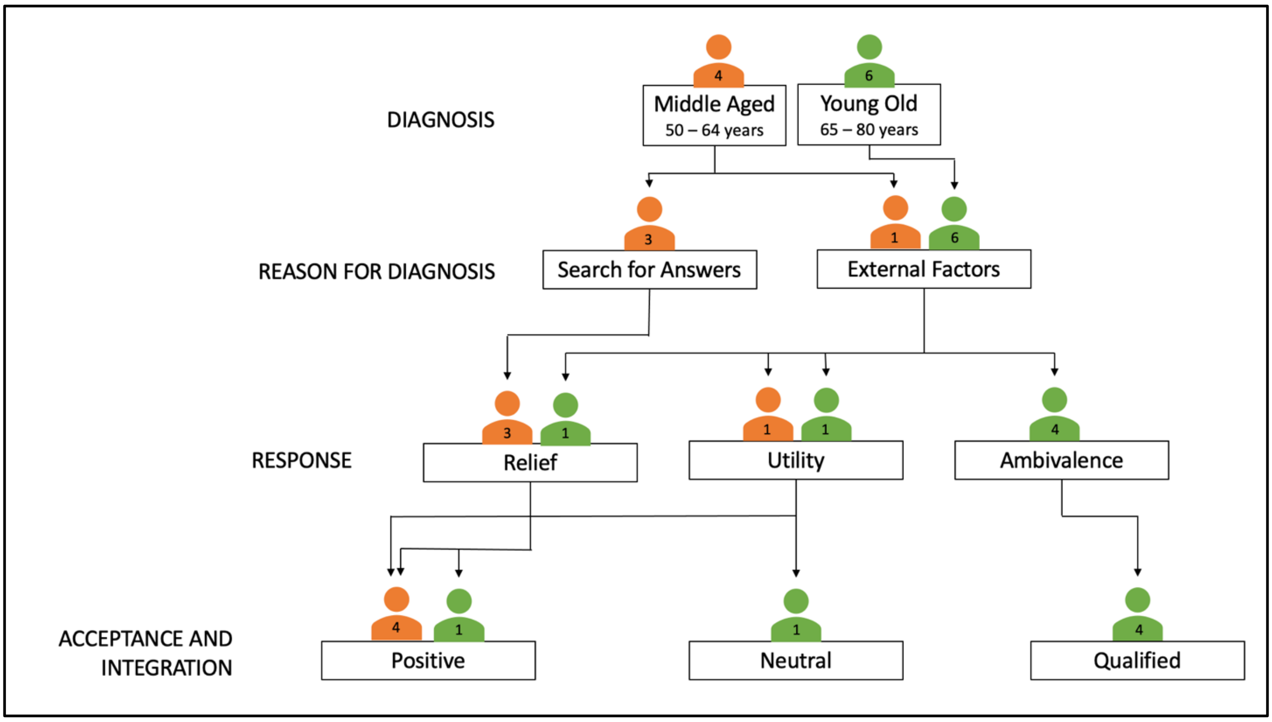
5.1 Sub-Theme 1. Pathway to Diagnosis

"It hurt, but it also made sense" **– Anne, 69 years**

Diagnosis was a theme in all interviews and was the term used by participants, irrespective of whether it related to informal diagnosis, in the form of self-identification, or formal diagnosis. Strikingly, pathways to diagnosis or self-identification were varied across the corpus but reflected trends in participants' age and life experiences as illustrated in Figure 1. While young old participants' pathway was via external factors, and was met with ambivalence and a qualified acceptance, middle-aged participants' diagnosis was the result of a search for personal understanding and was embraced with relief and acceptance. Just two male participants, one middle-aged and one young old, deviated from this pattern.

Figure 2

Participants' Diagnostic Pathways According to Age Stratification



Note. Numbered icons indicate the number of participants in each age category at each stage of the pathway.

5.1.1 Diagnosis

Although at the outset of the study five participants did not have a formal diagnosis of ASC, they self-identified as having "high functioning" autism or AS. None of these participants expressed an intention to seek formal diagnosis other than, pragmatically, what might be available through participation in the current study. As Doug explained, it "costs a lot of money to get the diagnosis". However, Margaret, in the young old group, declined to undergo a diagnostic interview for the purposes of the current study citing concerns about the negative impact she felt it would have on her sense of self[1]:

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[1] Margaret's response is discussed in more detail in Chapter 4 – Methodology

> *"[I] did find considering the possibility that I do fulfil the criteria quite disturbing. It upsets your idea of who you think you are".* Margaret, 69 years

Before coming to this conclusion, Margaret engaged in a period of self-reflection during which she weighed up the potential value receiving a formal diagnosis may have had for her autistic grandchildren, one of whom was "doing well and the other not so well", against the potential for harm to herself. For Margaret, diagnosis was driven by external factors. It was initially and primarily perceived within a family context – that is, it was a way in which she could make a positive and helpful contribution to her children and grandchildren's understanding and experience of autism – rather than at an individual level. However, ultimately, Margaret could not rationalise a family benefit to receiving a formal diagnosis that was great enough to outweigh the potential threat a diagnostic label posed to her sense of self:

> *"My conclusion is that I don't want to do it. I'm naturally helpful, but this won't help my family and, whether during or after, I think I'll find it very difficult, for several reasons".* Margaret, 69 years

5.1.2 External Factors

While all six young old participants came to diagnosis via external factors, for three (John and Anne as well as Margaret, discussed above) diagnosis came about unexpectedly after their children or grandchildren were diagnosed. These three participants reported that their discovery of autism and its characteristics explained aspects of their lives that they had been aware of but not realised were features of ASC. For some, this new knowledge also gave them insight and a sense of greater empathy with family members, as John explained:

> *"But I think it's probably just the realisation that I do have this surprising thing in my life [and it] can be useful in understanding some of my grandchildren".* John, 74 years

Two male participants, one young old (Ken) and one middle aged (Anthony), were not initially aware of their difference as something requiring investigation. While they understood themselves as perhaps being different from others in some respects, they perceived their difference as a strength that gave them a competitive advantage in their chosen professions; they were not troubled by their perceived difference. However, their partners were. Both Ken and Anthony were introduced to the concept of autism by their wives who were seeking to understand their husbands' odd behaviour and emotional detachment in an effort to address long-term and ongoing relationship issues. As they explained:

> *"She's [wife] investigated several things so ... I guess she's just started looking into it [ASC]".* Ken, 66 years

> *"It was all driven by ... uh years of [wife] and I trying to work out why I did weird things".* Anthony, 54 years

Consideration of an ASC diagnosis was brought to the attention of the two remaining young old male participants through other external channels. In Charles' case, a friend who was concerned for his ongoing mental health and social difficulties suggested he might be on the spectrum and, if so, eligible for support. As a teacher, Doug recognised autistic characteristics in his students' learning plans that very closely resembled his own experiences throughout life. This realisation, coupled with marital relationship concerns, led to a self-diagnosis of AS.

5.1.3 Search for Answers

By contrast, three of the four middle aged participants arrived at their ASC diagnosis as the result of a more deliberate personal quest to find an explanation for why they felt so different and out of step from other people and the world around them:

> *"You know when you're **not** diagnosed and you just know ... so many people have said that [breath] you just go through life ... um ... feeling a-a total misfit and not knowing even **why** you're a misfit ... and its horrible".* Paul, 53 years

Notably, despite the different routes taken, diagnosis for a number of participants took years and involved many missed opportunities, the distress of mis-diagnoses, and little helpful support from health professionals:

> *"I said, 'I think I've got Asperger's or something ... my wife thinks I've got Asperger's. She said I'm depressed, you know'. He said, 'Oh' .... He said, 'Well, if you are it's too late to do anything about it', and secondly, on the depression, he said, 'No, no'... he said, 'You don't present that way at all.'"* Ken, 66 years

Rose's experience, even though she was already in the health system due to mental health issues, was similarly unhelpful and drawn out over time:

> *"And when I finished this [counselling] ... after a year ... when I got my diagnosis. Nothing to do with autism ... I was going to have some kind of follow-up at home, and after they said, 'No, not for you. I think you're within the Autism Spectrum', and they started surveying and then I got the diagnosis. I'd been through three ... diagnosis ... until I got it.*

> *And all … all of them were on character deficiencies [laugh]. So, I got a character deficiency [laugh]. and Asperger's was my third or fourth diagnosis".* Rose; 57 years

5.1.4 Response and Acceptance

Beyond a commonly expressed sense of regret, reaction to diagnosis was as varied as the number of participants in the sample, as they all came to it from different perspectives and for different reasons. Nonetheless, for most participants receiving a diagnosis of ASC was a relief because it provided an explanation for their lifetime of difficulties and feelings of difference:

> *"It was quite a relief in a lot of ways to explain bits of my behaviour that people found strange that I didn't".* Doug, 69 years

However, for all but two of the young old sub-sample of participants relief was combined with an ambivalence about diagnosis, and acceptance of it was cautious and qualified:

> *"Yes, so* **in a way** *I'm glad I found out when I did and I'm glad that had … you know [but I] obviously had to deal with it then and was very down about it all".* Anne, 69 years [Author's emphasis]

> *"I guess I was … it took me back a bit, I must be honest. I was a bit upset about it".* John, 74 years

The two young old female participants found diagnosis particularly difficult. They described it as a threatening experience which triggered a variety of negative responses, including shame and embarrassment. Anne explained that coupled with the shame – "*The only thing was that I'd been diagnosed but I was a bit ashamed of it. […]"* – there was a reluctance to talk about her diagnosis:

> *"But, but, it was never spoken about and I would have liked to have been able to say, 'Yeah, I've had a diagnosis of that and I understand,' but I just … it was too frightening for me, you know too confronting".* Anne; 69 years

Margaret's response was similarly negative: "*I did find considering the possibility that I do fulfil the [ASC] criteria quite disturbing".* Indeed, as alluded to earlier, for Margaret the prospect of undergoing a formal diagnostic assessment was too confronting, even though she self-identified as being on the spectrum and was heavily involved in the care of her autistic grandchildren. A formal diagnosis risked distorting her sense of self and reducing positive sources of personal and family pride – high intellect, eccentricity, uniqueness – to a common denominator, a "label", which she associated with negative characteristics. As she explained:

> *"I felt quite confronted, naturally. 'Cos you think you know who you are and then suddenly somebody's saying you're something with a label on it. That's not the way most people are".* Margaret, 69 years

Similarly, a negative reaction to diagnosis was also described by Ken, who grappled with implications of his diagnosis that were irreconcilable with his self-identity and the life he had lived. He did not see that diagnosis brought relief or provided solutions to the difficulties in his life:

> *"I think all Aspies probably suffer from, you know, this is not really me, you know? And I guess I'm one of those. ... I didn't find it a relief. I don't find it ... I think some people find it as a bit of an excuse for poor behaviours. I don't feel that at all. I don't feel it's a relief because I don't see that diagnosis is any great panacea".* Ken, 66 years

By contrast, all of the middle-aged participants, and just one old young male, reacted more positively to their diagnosis; they were able to accept it and integrate it into their self-concept. For these participants ASC "*fit, so I kind of wear this one quite happily*" (Jane; 55 years), and provided validation for their sense of difference in a positive, understandable way, rather than a negative way:

> *"And I said, 'No no n-* ***this is it!*** *This ... explains why I'm so bloody strange and difficult! Honestly it's wonderful!'"* Paul, 54 years

For some, diagnosis also provided vindication of their difference and was perceived as permission to stop trying to alter the way they are in the world, or to conform with society's ideas of "normal". Rose explained that "*It doesn't change anything, I just know. I am what I am and you know what I am*". For Jane it triggered a positive reframing of what she had previously perceived as failings:

> *"Actually, that was one of the things with getting the diagnosis ... it made me think 'Oh this isn't a character flaw, this is just how I am'. I could try until the cows come home but can't actually change this ... whatever I do. That was actually quite a relief to have an excuse to not try so hard".* Jane, 55 years

Finally, Charles (young old) and Anthony (middle aged) reacted to their diagnosis from a purely utilitarian perspective. These men perceived formal diagnosis as a means to an end in the achievement of employment goals or resolving relationship issues; diagnosis was neither a relief nor unsettling, but it was potentially useful. While Anthony happily accommodated autism – albeit explicitly, "high functioning" or AS – into his life, Charles remained emotionally neutral about it:

> *"I thought ok if I can get any sort of medical classification that helps me move forward, I'm in it. So, I don't particularly care what the opinion or diagnosis of autism and Asperger's is um… I know all my life I have not been like other people. Um I've accepted that. The fact that there is now a classification to which I seem to fit seems useful".* Charles, 67 years

5.2 Sub-Theme 2. Difference

***"A unique difference"* – Anthony, 54 years**

Although pathways to diagnosis were varied across the sample, the underlying sense of a lifetime spent feeling different from others was a universal sub-theme endorsed by all participants except Ken. Participants reported having perceived themselves as different, but lacked a framework or precise understanding of that difference that allowed them to put it into context within the world around them. Difference was characterised as "not normal", "weird", "crazy" and "strange". This sense of being different from others was something participants had identified about themselves from a young age, and it had not changed with time or life experience. For instance, Anne recognised her difference from an early age, and it was something about herself which she felt had informed her whole life experience:

> *"I didn't understand myself. I didn't ... right from the start I was always very strange… I've been trying to ... what do they say, um, 'be normal' [laughs] all along".* Anne, 69 years

Participants discussed "normal" as a benchmark against which they had measured themselves throughout life. Although they were aware of being different from, or not quite meeting this benchmark, they grappled with the common concept of "normal" in the context of their own sense of self and how it related to their personal experience of normal. For some this caused confusion. As Paul put it, *"I'm abnormal and yet I'm not abnormal*". This confusing schema was experienced by most participants, particularly during early and middle adulthood, before they reached a level of equanimity in older adulthood which brought with it an understanding of self and reframing of "normal". As Rose articulated, "*I'm not **abnormal**. I'm just different*".

However, not all participants viewed their difference negatively, even in their younger years before they understood about ASCs. Rather, they had rationalised or understood their difference in terms of the context of their life situation. For some their perceived difference from others was simply just the way they were. For others it was viewed through the prism of culture and family rather than individual difference:

> *"And we [family] thought we were special. We didn't realise it was a diagnosis [laughs]".* Margaret, 69 years

Whether their sense of being different was problematic during childhood and throughout life, or something they took in their stride, by older adulthood all participants had reached a pragmatic understanding of it within a positive framework. In this sense, participants were able to frame ASCs as reflecting difference rather than disability:

> *"I see it as a wiring issue, and I don't see it as a bad thing, and I don't actually think it is a wrong thing. I think it is just a different thing. That's just how it is. And it has benefits".* Jane, 55 years

> *"A unique ... uh, neurological pattern ... um, a— that people have and I've actually never seen it as a disability. It is a unique difference that sometimes makes it difficult for that ASD to slot into, um, concepts of norm — of, of normality".* Anthony; 54 years

5.3 Sub-Theme 3. Family Patterns

"So maybe it's in the family" **– Ken, 66 years**

In discussing their pathways to diagnosis and seeking to contextualise it within their life experience, most participants referred to family patterns and the hereditary nature of ASCs. Seven participants were parents and grandparents and, for four of these individuals, diagnosis was the result of children or grandchildren receiving a diagnosis:

> *"There was never a diagnosis or anything until suddenly within I think six months both of them [two grandchildren] Someone –* ***completely*** *different people – had said ... um ... you know ... they got Asperger's".* Margaret, 69 years

Unlike the other participants with autistic children and grandchildren, for Anne her likely genetic influence on the diagnosis of her children was deeply distressing. She experienced grief at diagnosis, and attributed the guilt, self-blame, and remorse she felt as contributing factors to her later-life onset of depression:

> *"It took me a while to realise ... with a real* ***bang*** *... that these two children that had out of five children ... where the heck did this come? And I realised that it came from me and that* ***really****, REALLY hurt. It did. I felt like I'd done something* ***dreadful*** *... I'd passed this thing on ... you know ... and it took a long time to get over".* Anne, 69 years

5.4 Sub-Theme 4. Gender Roles

***"You know now it's so different with a woman, isn't it?"* – Anne, 69 years**

All the women in this study understood their autism and its impact over the course of their lives in the context of their gender. They reported experiencing an additional lifelong burden of social expectation in relation to conforming to family female stereotypes such as "daughter", "wife" and "mother". These were roles requiring social skills, duties, and nuances which did not necessarily come naturally to them. The women reported recognising early in life that they did not conform to social expectations of females, such as feminine manners or interest in their appearance. While Anne revealed she had always seen herself as "gauche" and Margaret noted she was not "urbane", Rose summed it up more definitively:

> *"I will never be a lady. I will never look pretty. I will never be able to find a nice frock, high heels and so on, and go out and let my hair down, and look pretty and have a nice party. That's not me. I won't be able to do that".* Rose, 57 years

Indeed, some of the women reported that, as they grew up, they instinctively felt more comfortable in male social groups, where any perceived differences were masked by their gender and a common interest or pursuit, making social interaction easier to navigate:

> *"I think even in secondary school I felt like I was different from the others. I sort of hung out with the boys more".* Jane, 55 years

Margaret had a similar experience when she went to university. Being a part of a male social group conferred twin benefits – it freed her from the stress of needing to conform to aspects of female social expectations she found puzzling, and allowed her to concentrate instead on her intellectual interests"

> *"But guys don't judge things the way women do, and they interact completely differently. And all these people, everybody just about who was there [at university], wanted to be there 'cos that's all they ever wanted to do. So we were all looking at life from quite a different perspective".* Margaret, 69 years

Nonetheless, at various life stages gender roles and social masks, such as wife and mother, were consciously adopted by all the women as an avenue through which a positive social identity could be achieved. For the three women who had children, their role as a mother was a particularly important source of self-identity and self-worth:

> *"The … one thing I wanted to do was to be a successful wife and mother, you know, so I made the family number one".* Anne, 69 years

All three mothers reported that parenting was something into which they had channelled huge effort. Jane explained that she believed the focus and attention she applied to parenting was attributable to her ASC, particularly her encouragement of individuality and respect for difference in her children:

> *"I think I was a very understanding mother. A very tuned-in mother. Knowing where they're at and kind of meeting them there. Respecting them as individuals not just telling kids what to do. And I think that's a part of the Asperger's, not just doing what everyone else does but thinking it through and finding your own way to do things".* Jane, 55 years

This strong focus on the mother role was also evident in the stories of the other two mothers in the study for whom the needs and welfare of their children had been all-consuming, and often came at a personal cost:

> *"Talking to her [sister-in-law] about the past and she said, '[Name], you lived for that family. You … you were so totally devoted and immersed in your family and your husband, your children. There was no room for anything else'".* Anne, 69 years

It was only in later life that Margaret was able to step back and put her own needs before her children's, as she explained:

> *"I was doing it for the girls, and you know when they cancelled the [diagnostic] appointment I went, 'Well I don't have to do this anymore'. Once I would have persisted".* Margaret, 69 years

Motherhood was not straightforward in other ways. These mothers reported additional uncertainty and stress associated with identifying and understanding the social norms of parenting:

> *"I had friends with young children, and I would sort of …* ***learn*** *from them, but I wouldn't … but I didn't ever say 'I'm learning from you' or 'What would you do in this situation' … I watched them and I would think 'Oh, OK, that's what I've gotta do' but it was all in my head … it wasn't even conscious, you know?"* Anne, 69 years

Working out what to do was only part of the challenge. As Jane revealed, knowing which "rule" to apply and when was an additional complexity to daily routines:

> *"I used to hate after-school pick-up. You know when they all want to go to somebody's place at short notice and I know I had organised 'taking him to basketball' and 'we're having this for dinner' and you know I have a plan in my mind ... um so part of it is the change of plans but also the not knowing what's socially acceptable ... the response. Like, am I supposed to say 'Yes' or 'No'? Do I have to stand here and talk to you, or do I pick up the kid or honk and the kid comes ... [laughs] you know ...* ***so*** *many rules that, well, not* ***rules****, but there are so many different ways of doing it".* Jane, 55 years

There were other gender-specific difficulties. Both Anne and Margaret believed that vulnerability throughout their lives had exposed them to domestic violence. One of these women was sexually abused by a close family member, and revealed that she had spent her life trying to understand why it had happened. She attributed her experience directly to having ASC"

> *"I think well I was vulnerable because I had Asperger's and I was vulnerable and that's why it happened".* Anne, 69 years

For the two younger women, a similar sense of vulnerability manifested itself in a lifelong reluctance to trust people, other than their closest family or friends, as a means of self-protection. Jane's view was combative – "*I never trusted anybody, thought that wouldn't be a thing. Why would you give anyone that ammunition about yourself?*" but for Rose, who had remained single all her life, lack of trust left her vulnerable to loneliness:

> *"I think I couldn't cope with the breaking up and losing people. Enlisting that much trust and then losing people. No ... I won't risk it. Better to be alone".* Rose, 57 years

5.5 Sub-Theme 5. Intellectual Pride

"I think I'm very intelligent" **– Jane, 55 years**

All participants, with the exception of two (John and Doug), clearly identified with, valued and drew a sense of confidence from their high intellect:

> *"I have always liked the idea of being a polymath ... and ... I ... I take considerable pride in being able to jump from one profession specialism to another".* Paul, 53 years

For these participants intelligence was an intrinsic part of their self-identity, and by extension it was integral to a positive, and acceptable, interpretation of the "high-functioning" (as it was termed at the time of interviews) end of the autism spectrum:

> *"But that's what I think of when I think of autism. Not not somebody differently abled, probably got a pretty high IQ ... who could do most things except be good socially, you know?"* Anne, 69 years

In most cases, participants' pride in and value for their intelligence was reported with a sense of superiority or arrogance, and in a way that suggested an apparent lack of insight into how their representation of their intellect might be interpreted by others:

> *"...started the process of looking at me having ... an IQ of about a hundred and twenty nine or something and ... knocking all the socks off all those calculation things ... which I expected everybody else should be able to do as well".* Anthony, 54 years

> *"I mean... yeah ... having done three degrees including a PhD obviously you're not dumb. So, um, so yeah, that's always been something y'know, a trait that I knew that um in terms of intellect that I could run circles round the majority of people that I interacted with and that's still the case".* Paul, 53 years

The extent of insight into their intellectual arrogance varied across the sample. Some participants acknowledged that they had lived life with an inherent belief in their intellectual superiority. While Doug thought *"everyone else was wrong and I was right",* Charles' perspective was specific: "*...intellectually I find them trivial, which sounds ... which sounds superior but ...*".

However, Anne acknowledged feeling remorse and had greater insight when she reflected, later in life, on how she may have come across as intellectually arrogant in the past:

> *"... he [potential boyfriend] didn't seem very clever ... he sort of ... you know, and there's that sort of almost ... superiority...? I mean who the heck was I that I had these delusions of how, you know, how above and separate I was, you know? It was kind of weird".* Anne, 69 years

A number of participants reported that they were not bullied at school. They attributed other students' and teachers' respect for their intellectual abilities in the classroom as a protective factor, as Margaret explained, *"And the other thing was ... I wasn't one of the stupid kids at school. So... it kinda protects you in a way".*

Intellect also informed life decisions as adults. The pursuit or not of higher education, and employment opportunities were taken according to whether they accommodated intellectual interests and strengths. This was particularly so for Ken who was highly focused on his career, "*I thought they were really smart people you know ... and ah so I started working there*". For some participants, their intellectual abilities continue to be an important source of pleasure and purpose in later life:

> *"I've always been interested in things of the mind and now that I'm retired of course I have lot of time to devote to [my interests]".* Margaret, 69 years

5.6 Sub-Theme 6. Shared "Aspie" Identity

***"'Cos we're similar Aspie sort of people"* – Doug, 69 years**

As referred to above, participants' identity in the context of ASC was contingent on their understanding of, and strong identification with, Asperger's syndrome as a condition that was distinct from autism, and characterised by high intellect and a different, not dysfunctional, way of thinking:

> *"I've never thought it was a really negative thing, but I guess maybe that's because I've identified more with Asperger's than ... more severe autism".* Jane, 55 years

> *"Certainly, then when they started splitting it into high functioning… or ASD that suited me much better".* Anthony, 54 years

While there was acknowledgement of a spectrum of autistic conditions, some participants – irrespective of age group – were uncomfortable with the absorption of Asperger's into the broader term Autism Spectrum Condition in DSM-5, and with it the perceived blurring of lines between autism requiring high levels compared to low levels of support:

> *"I like that you said 'condition' and not 'disorder' [laughs]. Can we get that in the DSM for next time? [laughs] Can we have 'Asperger's' back? [laughs]".* Jane, 55 years

For Margaret and Anne, both "young old", the distinction related to their response to diagnosis – "*[Asperger's] is better than saying autism, 'cos it makes you feel worse"* (Margaret, 69 years) – and disclosure:

> *"I'm not so open about the Asperger's. In a way now that they talk about it on the autism spectrum it's kind of awkward because I've never seen it as autism. I've seen some really severely autistic people".* Anne, 69 years

In talking about their AS, participants used language, such as the frequent use of the word "we", to denote a shared identity and membership of a distinct group within society. This membership was perceived as privileging participants' support for, and understanding of, individuals on the autism spectrum.

> *"I think with my mild Asperger's I probably have a better understanding of other people's Asperger's".* John, 74 years

Notably, a number of the participants used the term "Aspie", a derivative of Asperger's, when referring to themselves and also to identify or categorise others. The term was applied as a shortcut to describe characteristics, skill sets, and abilities. Although heavily reliant on stereotypes, the term "Aspie" was invariably used as a positive, affirming label:

> *"[laughing] It's just ... an Aspie ...Aspie bloody ... bloody ... we're tryin' to make sense of the world [laughing]".* Doug, 69 years

In some cases, the label "Aspie" was also used more broadly as a stereotype to categorise others perceived to be somehow different, or not conforming to social norms. Participants were enthusiastic in claiming people in the world around them as part of their Aspie group:

> *"And the [psychologist] claims not to be "Aspie" but I think you have to be a bit Aspie to understand things…".* Doug, 69 years

Not all participants identified with the term "Aspie". Two participants, Margaret and Charles (both young old) had only recently become aware of ASC and were in the early stages of understanding it as a condition generally, and more specifically in relation to themselves. One other participant was the only non-Australian in the study, suggesting the "Aspie" moniker may be a peculiarly Australian cultural descriptor for individuals on the autism spectrum.

Finally, although the theme of shared identity was strong across the corpus, participants discussed their ASC in the context of it being just one aspect of who they are. For Ken, who identified as Aspie but with a degree of ambivalence, this distinction was particularly important because "*there's a lot more to me than Aspie. And same with everybody you know".* He elaborated:

> *"I just think everyone needs to be more cognisant of the fact that being on the spectrum is not the total person".* Ken, 66 years

5.7 Discussion

Analysis revealed an overarching theme of negotiating diagnosis and an autistic diagnosis in later life comprising the sub-themes pathways to diagnosis, difference, gender roles, family patterns, intellectual pride and shared identity. While some of these themes are broadly consistent with previous literature, they also suggest additional complexities to receiving and accommodating an autism diagnosis as an older adult that may be influenced by developmental life stage.

Participants' pathways to diagnosis and their subsequent responses and acceptance of an autism diagnosis or identity followed a distinct pattern according to age, as illustrated in Figure 2, rather than time since diagnosis which has been suggested as a potential factor in other studies (Jones et al., 2014). As other studies have found (Jones et al., 2014; Geurts & Jansen, 2012) all middle-aged participants in this study, except for Anthony, came to diagnosis as the result of a personal quest to understand why they felt different from others, and found aspects of life difficult. By contrast, Anthony and all the older participants were not seeking self-knowledge even though they acknowledged having similar life experiences to those of the middle-aged group. The suggestion that they were autistic was unexpected and introduced through external sources, either as a result of diagnosis of a child or grandchild, or due to prompting from a partner or friend. This is a less common avenue for initial referral for adults (Jones et al., 2014), although older adults are increasingly referred for diagnosis as a result of greater community awareness, or partners' exploration of autism as an explanation for marital problems, (Brugha, 2018; Happé et al. 2016; Tantam, 2016).

Given the distinct pattern in pathways to diagnosis it is perhaps not surprising that in this study variability in response to, acceptance and integration of an autism diagnosis also trended according to age. All participants found that diagnosis helped explain aspects of their life experiences and feelings of difference. Responses, particularly in the middle-aged group, ranging from relief to regret, vindication, and – notwithstanding concerns about stigma and negative stereotypes – an ultimately positive autistic identity were mostly consistent across the corpus and expected (Bury et al., 2020; Cooper et al., 2017; Webster & Garvis, 2017; Hickey et al., 2018; Jones et al., 2014; Leedham et al., 2019; Treweek et al., 2019). However, unlike the middle-aged participants, and in stark contrast to the results of other studies which found an overall positive association between self-esteem and autistic identity (Cage et al., 2018), the young old participants' responses to diagnosis were distinctly contradictory. These older participants were ambivalent about diagnosis; there were positives but it was also confronting, and acceptance of it was qualified. With the exception of Doug, rather than integrating an autistic identity, the older participant group understood autism as just one part of their identity. A pressing concern for the older adult group was the potential for diagnosis to negatively impact on their sense of self. As Margaret explained, "It upsets your idea of who you think you are". Indeed, a negative perception of "autism" as opposed to the preferred "Asperger's" across the corpus highlights that the Autistic Spectrum Disorder diagnostic label in the DSM-5 continues to be a contentious issue for some, with its elimination representing the removal of an important distinction in some autistic individuals' understanding of autism identity (Rosen et al., 2021).

The clear trend in response to diagnosis according to age group is a novel finding as it suggests a possible association between stage of life and acceptance and integration of diagnosis. Indeed, this pattern of results – middle-aged participants responding to diagnosis with relief, acceptance and integration into their lives compared to young old participants responding with ambivalence and qualified acceptance – maps neatly onto the SOC metamodel of lifespan development. According to this framework, selecting and focusing on life domains that are of high personal importance (e.g., maintaining a stable self-identity versus accommodating a diagnostic label) in the face of environmental demands and other uniquely individual factors is a process inherent in adaptive ageing (Baltes & Baltes, 1990). It provides a theoretical perspective to account for the heterogeneity in successful ageing that accommodates individual differences and may therefore be a useful framework within which to understand variability in responses to and integration of an autism diagnosis in later life.

The classic life-span theory of socioemotional selectivity (SST; Carstensen, et al., 1999) and its propositions that the selection of goals that are emotionally meaningful and satisfying in the present moment are prioritised over seeking new information for personal growth or knowledge goes further in providing a possible explanation for the distinct age-related differences in response to diagnosis found in this study. Within this framework older adults, such as the young old participants in this study, may have reached a stage of life where they are content to optimise positive emotional experiences rather than focus their efforts on potentially emotionally destabilising activities such as seeking a diagnosis that risks threatening their emotional equilibrium. In being confronted with such a situation, it may be difficult to embrace new information that was not sought and does not directly meet individual emotional goals. Conversely, it makes sense that individuals in middle-age may still be seeking self-understanding, possibly through a diagnostic process that addresses a need for knowledge, helps explain difficulties in their past, and sets a positive path for the future.

Reluctance to embrace an autistic identity or diagnosis in older adulthood, as illustrated by Margaret and Ken's experiences, highlights how diagnosis has the potential to emotionally destabilise self-identity with little other obvious benefit, at least from the perspective of the older individual, and provides the example of lived experiences to illustrate how the drawbacks of diagnosis may outweigh any perceived benefits (Sonido et al., 2020). Nonetheless, where co-occurring conditions exist, such as mental health problems, there may be benefits to a diagnosis such as ensuring suitable treatment is provided (James et al., 2006).

The experiences and perspectives of young old participants presented here provide insight into how navigating the tension between perceived personal drawbacks and potential therapeutic or clinical benefits may be challenging for health professionals. Considering diagnosis within a lifespan developmental model of adaptive ageing may be useful for understanding and anticipating the potentially negative impact it can have in later life depending on the developmental stage and life goals of the individual. Taking this perspective gives weight and perhaps a theoretical context to clinical considerations already raised about when diagnosis of ASC – as opposed to some other co-occurring condition – is warranted for older adults, what purpose it may serve, who wants a diagnosis in later life and why (Brugha, 2018; James et al., 2006; Tantam; 2016).

How the participants in this study eluded earlier diagnosis is of interest. Despite experiencing lifetime mental health difficulties and other social and relationship concerns all, with the exception of Anthony, experienced missed diagnosis or mis-diagnoses. These experiences confirm the continuing problem of health professionals' general lack of awareness or understanding about the presentation of ASC in adults, its frequent co-occurrence with mental health problems, and the potential for diagnostic overshadowing (Happé & Frith, 2020). At a personal level, participants' reported frustrations with health professionals' lack of awareness and knowledge about autism in adults is consistent with findings in other studies and concerns raised within autism communities (Bradshaw et al., 2019; Jones et al,. 2014; Lai & Baron-Cohen, 2015; Leedham et al., 2019; Unigwe et al., 2017; Zerbo et al., 2015). Along with other barriers to diagnosis reported by participants, including a lack of perceived worth in seeking a clinical assessment, and prohibitive cost, both of which have also been noted in previous studies (Lewis, 2017; Robison, 2019), it seems that unfortunately provider and systems level failures clearly continue to be barriers to diagnosis and treatment accessibility (Bradshaw et al., 2019). Addressing this must be a priority, particularly as community awareness of autism increases and more older adults seek healthcare support for diagnosis and associated issues.

Another explanation for participants' missed diagnoses could be that they behaved and blended into the world around them sufficiently well enough that obvious differences suggestive of an ASC were camouflaged. While there has been a strong focus in the research literature on the negative aspects of masking and camouflaging (Bradley et al., 2021; Hull et al., 2021; Livingston et al. 2019b), the findings in this chapter provide evidence for potentially protective factors that may have enabled the autistic adults in this study to reach older age without coming to clinical attention. Although all participants reported feeling different from others from a young age as a source of personal pain, a finding in line with other qualitative studies on older adults (Hickey et al., 2018), their sense of difference was also inextricably interwoven with characteristics that were viewed positively. That is, for some participants, such as Charles and Margaret, their perception of being different pre-existed their understanding of autism and was understood in a positive light within the context of family background or intellectual superiority. For instance, Margaret lived relatively happily with autistic traits that she and her family viewed as evidence that they were “special”. Charles was not bullied at school, and did not feel excluded, because his academic achievements were respected by his teachers and peers. It was only when their situation in life changed, or external factors came into play, that their functioning was impaired or in some other way brought about the possibility of an autism diagnosis. That some participants in this study reported successfully negotiating much of life despite feeling different may support some researchers’ suggestion that autism be conceptualised on a dimensional continuum (Happé & Frith, 2020; Lai & Baron-Cohen, 2015) with a diagnosis based on behavioural assessments coming and going depending on an individual’s life stage and context. That is, as was the case for the participants in this research program, an individual may have periods of life in which they live happily with their autistic characteristics but at other stages these same characteristics may be the cause of impaired functioning, meaning the severity of their autism presentation may rise and fall depending on contextual or life stage factors.

Participants’ adaptation to the world around them hints at a possible “flip-side example” of Lai & Baron-Cohen (2015)’s description of challenges for autistic individuals being the result of poor fit between the individual and their environment. For all participants there were periods of time in their lives when they were surrounded by others who were similarly “different”, such as other family members with similar characteristics, or the context within which their “differences” were experienced was supportive or suited their skills and abilities. Notwithstanding periods of mental illness, these environments may have provided opportunities that enabled them to develop their sense of self and self-efficacy such that they were able to experience relatively fulfilling lives encompassing successful personal relationships and careers (Webster & Garvis, 2017; Livingston et al., 2019b). This is encouraging further evidence that a supportive person-environment fit can give autistic people the opportunity to enjoy successful and productive lives (James et al., 2006) and that, based on behavioural criteria, a clinical diagnosis may come and go (Happé & Frith, 2020).

Although gender was not a specific line of enquiry in this explorative research, it emerged as a distinct sub-theme particularly in terms of the female participants’ understanding of their autism. The findings presented here may further our knowledge of the particular challenges to diagnosis associated with female camouflaging (Happé & Frith, 2020) and provide a unique lifespan perspective to what is known about the older autistic female’s experience. The women in this study described feeling social pressure throughout their lives to conform to gender stereotypes which is consistent with the reports of younger women in other studies (Hull et al., 2017; Milner et al., 2019). The strong focus on the "mother" role reported by some of the women in this study gives insight into the ways in which females continue to adopt socially acceptable and age-appropriate special interests into adulthood. It is easy to see how successfully fulfilling these roles enabled these women to remain hidden in plain sight and likely contributed to their delayed diagnosis. Indeed, the female masking and role modelling behaviours described by them support theoretical conjecture that relying on behavioural symptoms to identify autism is a key challenge associated with the under-diagnosis of women (Brugha, 2018; Happe & Frith, 2020).

The two older female participants' reports of sexual abuse and domestic violence were deeply concerning but perhaps not surprising as they are in line with research findings that autistic adults are more vulnerable to these types of abuse, as well as victimisation and bullying, than typically developing adults (Griffiths et al., 2019). However, there are few female first-hand accounts, such as the experiences reported here, in the literature. These women's experiences are consistent with reports in other qualitative studies of female participants' vulnerability to predatory behaviour and sexual abuse (Milner et al., 2019; Webster & Garvis, 2017) and build on them by providing insight into how such traumatic events were internalised through withdrawal and role adoption, and had long-term implications across the lifespan. It may be that other autistic women also use coping strategies such as camouflaging and masking as a way of dealing with abuse. Although not reported by participants in this study, given the vulnerability of autistic people to victimisation and bullying such as that reported in this study, it seems likely that the incidence of elder abuse may also be higher in older autistic adults. The development of assessment approaches aimed at identifying undiagnosed adults should consider the possibility that a proportion of victims of various forms of abuse seeking medical and social support may be undiagnosed autistic adults, and particularly undiagnosed women in cases of sexual and domestic abuse. Awareness of this may help identify vulnerable people in need of specialised support who otherwise might fly under the diagnostic radar.

Diagnosis in older adults has not received much research attention and more is sorely needed. However, it is hoped the findings reported in this chapter provide additional insight into the experiences of diagnosis and integrating an autistic identity in later life. Participants' reported experiences and insights offer invaluable clues to the risk characteristics and challenges of older adults seeking a diagnosis and autism-friendly services appropriate not only to their needs but also their level of comfort with a diagnostic label. It seems likely that there are additional complexities determined by nuanced but established differences in middle age and old age life stages such as those identified in typically developing adults. How or whether these stages of lifespan development and adaptive ageing apply to older people negotiating an autism diagnosis requires further investigation.

Chapter 6: Social Instinct

"The only thing that's changed is my awareness" **– Paul, 53 years**

This theme canvasses the changing experiences of these older adults' social functioning across the lifespan. Even before they were aware of or identified with autism, each participant had instinctively recognised early in life that their social abilities were different from others, and a defining and ongoing difficulty in their lives. Analyses revealed patterns in participants' experiences, perceptions and motivations which provide unique insights into how they have negotiated, adapted and responded to the social world as they age. These are explored through interconnected sub-themes at two levels. The first relates to participants' perspectives and experiences at the level of their inner world through the sub-themes of *lifelong impact*; *never changing*; *longing to belong*; and *social sensitivities*. The sub-themes *socialising is strategising* and *support* are representative of participants' outward focused experiences. Sub-themes and illustrative quotes are in Table 4 and their interconnections are represented diagrammatically in a thematic map in Figure 3.

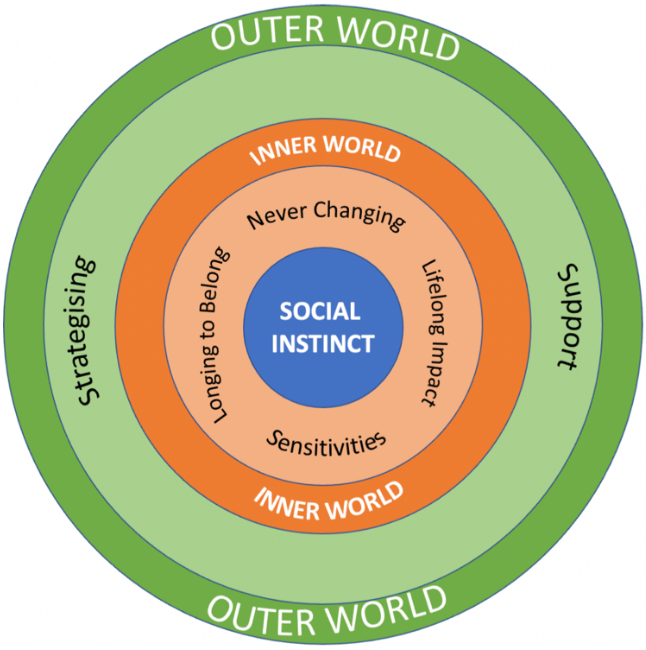
Table 4

Social Instinct Sub-Themes and Illustrative Quotes

Sub-theme	Illustrative Quote
Inner world	
Lifelong impact	*Social interaction is still difficult and will always be difficult I think*
Never changing	*Well I can't see any difference*
Longing to belong	*I really long to belong*
Social sensitivities	*I often understand how the other person feels and why*
Outer World	
Socialising is strategising	*It's all about learning how you are expected to behave*
Support	*Moral support is important*

Figure 3

Thematic Diagram Illustrating Social Instinct and its Interconnecting Sub-themes



6.1 Sub-Theme 1. Lifelong Impact of Difficulties

> ***"Social interaction is still difficult and will always be difficult, I think"* – Rose, 57 years**

Difficulties in social functioning were reported by all participants irrespective of age group or gender. However, the degree to which individuals were aware of and had insight into their difficulties varied across the sample. So too did their interpretations of social functioning; for each the *meaning* of social difficulties was different, highlighting the complexity of individual differences in the social domain. For instance, Ken was highly attuned to his difficulty with the demands of socialising, and the "effort required to communicate". He understood it as something that cost him at an individual level as generally fatiguing and something he could only manage in small doses, and at a relationship level because his aversion to it was a troubling point of difference from his wife who found frequent social interactions stimulating:

> *"I feel bit drained [socialising], you know. I do. And that's um … and I'm not just making that up 'cos it says in the literature but I've got a limit, you know? You can't take me out every other night and expect me to … I just … I get … it really drains me. [Wife] gets energised by it and that's where we have this huge difference, you know. But I feel very drained by it, you know, and I just need time to repair".* Ken, 66 years

Similarly, Jane, who was finding leaving the house increasingly difficult, found everyday incidental socialising challenging. Anticipation of inevitable casual social contact that would require "small talk", and then the small talk itself, were exhausting for her and compounded her reluctance to leave home:

> *"I don't want to meet people, I don't want to have to talk to people in shops. I think that's part of it. The small talk".* Jane, 55 years

But for John, while there was a desire for social interaction, the mechanics of it was the problem:

> *"I find it difficult to join into any conversations, you know and certainly if there's many conversations going on I'm gone, forget it. Forget it!".* John, 74 years

Likewise, Doug's social functioning difficulties related to reading social cues, but his awareness of this was intellectual rather than instinctual:

> *"I know I'm not [reading social cues], but I don't have a sense of it, if that makes sense [grin, small laugh]".* Doug, 69 years

By contrast, although Anthony too was intellectually aware that social difficulties were associated with autism and acknowledged that he might commit the occasional social faux pas, he didn't see this as a problem. This was consistent with Anthony's somewhat over-confident communication style in the interview:

> *"So the social ... uhhh ... awkwardness that everyone keeps asking about isn't... I don't think is me. But I do think I probably drop clangers and whatever, [but I] just keep rolling along".* Anthony, 54 years

In some cases, there were aspects of social interaction about which participants were not even aware. Ironically, in Mary's case, this was theory of mind:

> *"Once I learnt about theory of mind – it was probably only a few years ago – I don't think I actually ... had theory of mind until I was over 60. I mean seriously. It just ... it* ***never*** *occurred to me".* Margaret, 69 years

Irrespective of the type of challenge, or even the level of awareness, these lifelong social difficulties impacted variously on all stages and aspects of life, ranging from personal relationships and everyday interactions to employment scenarios. As Charles explained, while he was aware that his social style was different from others it did not concern him, but once he left school this difference became more problematic to manage and it impacted on his ability to find and maintain employment:

> *"And like I say, in school I coped with it simply by staying away from it. They accepted I was weird, I accepted that they were whoever they were, and we left each other alone. But when I have to go out there and get jobs … that has been the problem".* Charles, 67 years

In the workplace it added an extra layer of pressure for Ken:

> *"When I was working, I found out that I used to like … [I was] a bit of a backroom guy ... at heart, you know? Ah, but in my career I had to spend a lot of time not being a backroom guy. I always found it a struggle, you know? I always felt I was at the edge of my capacity you know?".* Ken, 66 years

For some, there was a sense of being constantly "on guard" in the social domain, even in later life and with close family members, as Anne explained:

> *"I still think I say the wrong things… I do … unfortunately and especially where … I feel like I'm walking on eggshells whenever our [adult children's families] are under the same roof […] you know and I'm thinking, 'I mustn't say the wrong thing, I've got to treat everybody really carefully'. I can't sort of trust myself to um come out with things".* Anne, 69 years

This problem was a common one, and a number of participants perceived that at times the origin of social difficulties was not one-sided but due to a lack of mutual understanding or perspective-taking by neurotypical social partners. According to Paul, "*I think that's … that is a **big** problem for non-Asperger's people for understanding where I'm coming from …".* John's experience of this echoed those of others. His description of misunderstandings in communication with his wife of 50 years provided insight into how this "double empathy" problem continues into later life even in long-term relationships:

> *"Frequently I will say something to [wife] meaning one thing and [wife] misinterpreting it for something completely different (same with what I think is a joke – or she sees as a joke), and it is mis-interpreted. This can cause a lot of angst and upset. And of course [wife] sees this as being my problem!! And me not being able to discern what I say or what she says correctly".* John, 74 years (via email)

Misinterpretations and the misunderstandings and tensions it led to with his wife were a constant tension for John. Relationship difficulties with his wife, particularly with respect to communication, were the reason for his participation in this research program and something he mentioned a number of times. His quest, and ongoing frustration, was that he was aware it was a problem, but still the misunderstandings occurred. This was a common experience amongst participants.

6.2 Sub-Theme 2. Never Changing

***"Well, I can't see any difference"* – Doug, 69 years**

These difficulties with social interaction and communication had not changed in any significant way throughout the lives of participants, despite deliberate and conscious efforts to develop an intellectual understanding of the "rules" of social behaviour. As alluded to above, John explained:

> *"I think the major thing is this socialising… is, is, is … an ongoing problem, minor or major, depending on the circumstances".* John, 74 years

All participants had reached a realisation that these difficulties were immutable:

> *"And … in thinking, look just a little bit more me doing a few more things and I'll buy another book … there's another five hundred page book on Aspie tribes, neural neuro tribes. I'll read that one. I'll add that to my hundred and ten others and my journals. I've got a metre high pile of journals and um … it's like, it's like … trying to … chase the tide".* Anthony, 54 years

This realisation was difficult for some participants, particularly the males who were in close emotional relationships, because there was a sense that by not being able to "fix" their perceived problems, they were failing to meet the needs and expectations of their partners:

> *"And I think my poor wife thinks that once they find what it is they can fix me. Can cure it […] And I don't think that's gonna happen. Understanding about something is one thing, changing it is a different thing … you know, 'cos it … to me it's not a choice…".* Doug, 69 years

By contrast, Ken and Jane reported that they believed their social difficulties had worsened over time. Both these individuals discussed this in the context of ageing and their sense that life transitions had exacerbated to some extent their "social" self-confidence. As Ken described it:

> *"My sense of it is you probably backslide once you get older you know. You move out of the work force and you're a bit more isolated".* Ken, 66 years

With the perspective of a lifetime of experience, Anne and Jane, both qualified teachers, were negative about the impact of social skill interventions developed to, as they perceived it, change autistic individuals. They expressed concern that interventions were a futile attempt to alter or suppress innate difficulties and abilities, and this placed an unacceptable burden on the current generation of children with ASCs. Anne's opinion was emphatic:

> *"[Psychologist said] if we can get children really young and help them to understand their life ... their classroom situation ... their whatever ... it sort of [will] not [be] as severe when they get older? But I don't know... People I've met they don't seem ... there's ... you know ... I don't think there's degrees of Asperger's. You're either Asperger's or you're not".* Anne, 69 years

Jane's view was also particularly strongly held. She had grown up in a large family in which entertaining and associated social etiquette were important, and something in which children were expected to be schooled. Throughout her interview she conveyed a pride in her ability to entertain guests at social functions, but now in later life she found attending family social events exhausting. There was a sense that with time and distance – and reflection – she had developed a lingering resentment for the expectations that had been placed on her in the past:

> *"I have some concerns about the long-term impact of early intervention on children on the autism spectrum. My limited understanding of the practice is that it is to improve the children's social functioning and ability to participate more appropriately in general society. As a person on the spectrum who was well trained in social behaviour from a young age and who still manages to pass as 'normal', my concern is that this early intervention may lead people to believe that, because a child/adolescent/young adult appears to function well socially, their need for ongoing support is diminished or non-existent. As one of the key features of an ASD diagnosis is that it is a life-long condition then, no matter how socially adept a person on the spectrum becomes, their autism remains and the cost of 'appearing' to be 'normal' actually places a significant strain on the person's resources".* Jane, 55 years (via email)

6.3 Sub-Theme 3. Longing to Belong

"I really long to belong" **– Rose, 57 years**

This sub-theme relates to the desire experienced by most participants throughout their lives to belong to a social group of some form or other, either emotionally or intellectually and, significantly, independent of family relationships. While family relationships were valued, there was a sense that these were perceived as predetermined whereas "true friendship" was a social relationship that was earned through genuine connection and regard based on individual qualities and irrespective of family ties or a sense of duty. There was regret for life lived having not experienced genuine friendship. John attributed his lifelong regret that he'd "*never really made genuine friends"* to being autistic:

> *"I think it [autism] means to me most of the time poor socialising and [not] making my own friends rather than making friends via my wife or in any other way".* John, 74 years

This yearning to belong, and the perception – or instinct – that genuine friendships eluded them, remained for some participants into older adulthood:

> *"I sort of think, 'Well, what about me? Why don't people ask me to do things?' You know?".* Anne, 69 years

But longing to belong was complicated. There was also acknowledgement that the *idea* of friendship, or being a part of a group, and the *reality* can be different; that "neurotypical" group membership can place unwanted or less enjoyable demands on the autistic person. As Rose put it:

> *"I feel lonely sometimes, yes. I ... Sometimes… There are times I really long to belong in a group or an occupation and er ... and er ... But er er I know myself too ... if I try to get like into a group, into an activity ... I find out "ohh, this doesn't function to me". I feel I'm letting the others down, because they let me into their group or their situation and I ... I try that and I disappear again".* Rose, 57 years

Notably, the concept of belonging did not refer only to emotional connection. Both Charles and Paul's longing to belong was driven by a desire to connect with others intellectually, rather than emotionally, and in a way that would give them an opportunity for intellectual stimulation or validation:

> *"All I know is that for myself I was always interested in a relationship that offered that potential [of shared intellectual experience]. Never found it".* Charles, 67 years

> *"I do seem to have an ongoing ... desire for some of that ...[intellectual] validation from people that have known me".* Paul, 53 years

In later life, however, most participants reported being less bothered by a perceived lack of belonging or friends than they were during earlier stages of life:

> *"They have these little cliques, and they do things away from [seniors' community group] and they're all ... and I'm not you know I haven't got that little friendship group, but it doesn't worry me now the way it used to worry me".* Anne, 69 years

There was a sense that with age and experience there was acceptance, and most participants, even John, derived more pleasure in spending time with their family or pursuing special interests.

Four participants did not express a wish to be more connected socially, despite reporting the same sense of difference and social confusion throughout their lives as others in the study. However, there was a distinct pattern of social connectedness from early childhood in these individuals: they had small close-knit circles of friends known to them since their early school years (three attended small, same-sex schools), and they had maintained contact based on shared history and common interests throughout life. There was a sense that with these friends there was complete trust and security, and no need to be any way other than the way they had always been. Social hazards were not a problem. As Margaret explained:

> *"The friends ... they just think you're you know, the way you are. I mean if you've known each other since you're 13 you just… that's just the way you are".* Margaret, 69 years

However, in the case of two of these participants, Jane and Anthony, despite having a small group of lifelong friends, their distinct preference was for solitude, independence, and a sense of autonomy. Although Jane maintained contact with her friends, she preferred not to be defined by the association but instead to *"break away; just somehow or other to be my own person".* Anthony too was completely emotionally and socially self-sufficient; he was happy to be independent and to do and be as he wanted to be:

> *"For me solitude ... is the only time when I can feel ... anything like relaxed. Yeah. Um ... I **honestly** don't know what… y'know the negative feeling of loneliness is".* Anthony, 54 years

6.4 Sub-Theme 4. Social Sensitivities

***"I often understand how the other person feels and why"* – Rose, 57 years**

Sensitivity in this context does not relate to sensory sensitivity, which is often a feature of ASCs, but to an emotional and moral sensibility characterised by awareness of and responsiveness to the feelings of others, and strongly held personal principles or moral conscience. In some respects, what participants described experiencing was empathy, but only Jane referred to it as such. Prior to her diagnosis, as she was seeking answers about herself, Jane read widely on Asperger's syndrome and although she recognised many characteristics in herself, based on stereotypes about

ASC and a lack of empathic feeling, she assumed she did not quite "fit" the profile: "*I have a lot of empathy so I mustn't be on the spectrum*".

However, contrary to the stereotype, all participants' life stories conveyed a sense that they had sensitivity or developed it over the lifespan, and it seemed to have had a strong influence on how they perceived and interacted with the world around them. Some participants reported being particularly sensitive to the mood or atmosphere around them, but not knowing how to manage it:

> *"And the air changed. And I knew it had changed but I didn't know what it was and sometimes I'd be in there and I would be trying to ... turn around a situation I didn't understand but I knew the air had changed in the [...] room".* Margaret, 69 years

Paul recounted similar experiences and provided further insight into the complexity of sensing atmosphere changes but, due to impaired social communication skills, having difficulty expressing, or acting on, it:

> *"I [have] always been* ***acutely*** *sensitive to people's state of mind or mood. Always. But ... it's specifically a blindness about them and me relating ... there's a blind... that's there so ... you know I can see that someone's looking tired or crestfallen or ... angry or ...* ***whatever*** *... there's no problem with ... y'know the common thing about [the] facial expression thing; none of that at all. In fact, it's the opposite. I'm* ***oversensitive*** *to all of that ... it's the lack of ability ... yeah is in ... understanding how my reactions have, y'know [how] my behaviour is going to ... affect another person".* Paul, 53 years

Indeed, as foreshadowed by quotes from John and Paul in the first sub-theme in this chapter, many participants were acutely sensitive to how their behaviour and intentions were often mis-interpreted by others or inadvertently hurt them. As Anthony explained:

> *"It honestly didn't bother me, but it absolutely distressed me that it was causing so much upset with [wife]".* Anthony, 54 years

In many cases participants' concern was for the negative impact of their social difficulties on close family members, rather than on themselves. This was nominated as the driving motivation for their quest to seek more information about autism through counselling, and for wishing to participate in the current study:

> *"I came because of the ... um ... kids and the grandchildren particularly, and ... um ... because you ... it would ...yeah I suppose it would be better for them if it were easier".* Margaret, 69 years

All participants indicated an awareness of the potentially negative impact social difficulties could have for others with autism. Drawing on their own life experiences, they were prepared to support and help others with ASCs, or those they perceived to be marginalised in some way, to avoid some of the unhappiness and stress they themselves had endured throughout life. In some cases, this was an intellectual process, such as Ken's compilation of a list of potentially problematic behaviours to be aware of that might "*be useful for me or for someone else in the future*". In other cases, the support was more practical, and driven by an understanding based on personal experience. As Rose explained in describing a scenario when she came to the defence of someone having a meltdown, *"I understood what she went through"*. She elaborated:

> *"And um she had a ... I saw her ... she was sort of verging on a meltdown because she just shut down completely and somebody commented on it, and I said leave her alone. She needs to cut out the world for a moment. It wasn't naturally my job to do it but just ..."*. Rose, 57 years

For Anne, too, the desire to support others was instinctive: "*But I said, 'I'm here to help you'*".

6.5 Sub-Theme 5. Socialising is Strategising

***"It's all about learning how you are expected to behave"* – Anne, 69 years**

This sub-theme outlines the range of social motivations and evolving strategies participants described using as they navigated the social world throughout life and as older adults. Strategies had been developed over time and honed, or in some cases abandoned, with the benefit of insight derived from hindsight and life experience. Even in later life, participants continued to be motivated to develop and deploy strategies to help them improve their ability to interact socially, although social goals themselves evolved.

The males in the sample who had partners were primarily motivated to develop strategies that addressed perceived difficulties in their relationships with their wives. As Ken explained:

> *"[Wife] used to make these criticisms and I just used to write them down. And um ... I try to address them I suppose in some way"*. Ken, 66 years

By contrast, the married women in the group did not share the same degree of partner-related social motivation.

But whatever the driving motivation for improved social skills, a pragmatic and intellectual approach to interpersonal interactions with an emphasis on learning how to behave socially was uniformly reported by most participants. This approach was based on a fundamental understanding that there was a lack of social instinct that required compensation. Participants described how since childhood they had continued to use and adapt compensatory strategies drawn from experience and research. However, even after a lifetime of doing so, many of these strategies remained effortful. Paul, Margaret, and Anthony each succinctly but uniquely described this approach:

> *"With life experience you learn the rules slowly and you learn to compensate for what isn't there by inherent nature".* Paul, 53 years

> *"Well you're able to work out that what you just did didn't work so you perhaps you better shut up 'til you work out something better".* Margaret, 69 years

> *"Um ... and I think I ... I've* ***read*** *extensively and over the years I've worked out ... ways to manage".* Anthony, 54 years

Creative adaptability was a feature of many strategies. A number of participants detailed how they purposively sought or initiated structured activities, social and work roles for themselves, often related to areas of special interest, or in environments that were predictable and therefore perceived to be manageable, to satisfy their need for social interaction. Becoming involved in community groups and taking on positions of responsibility within the workplace were revealed as deliberate attempts to connect with others and create a sense of belonging within groups chosen for their reasonably structured environments:

> *"I make acquaintances through other things like ... you know ... groups I belong to, you know ... I belong to several things – the environment, we do a lot of stuff politically, so I've sort of got a circle of people there you know ... aren't sort of friends as such, they're colleagues if you like".* John, 74 years

Some of these approaches, such as Doug's, were notable for their irony but nonetheless achieved the desired goal:

> *"I was President of the social club at [workplace] for about 5 years ... and I was a union rep".* Doug, 69 years

Doug enjoyed this form of social interaction; it provided structure and suited his preference for rules, but there was also a sense that he enjoyed the service aspect of these positions as well. As he explained:

> *"… just interested in keeping ahhhh people happy at [workplace] […] you know and things like that […] and sort of strong thing on what's wrong and what was right. That's why I got into the union I think".* Doug, 69 years.

But after Doug retired, he struggled to maintain old, or form new, social connections without the structure of the workplace. The other male retirees, John and Ken, had similar experiences whereas the women, particularly the married women, did not. For Ken, who felt emotionally vulnerable in his relationship with his wife, there was a stark contrast between social interaction in the workplace and at home:

> *"I think it's [workplace] a lot easier – those relationships, you know than your intimate relationships […] because they are very much more structured".* Ken, 66 years

There was a clarity and predictability to the "structure" of workplace social interactions that Ken preferred, and he felt more competent in his ability to meet the social expectations of his professional role than those of his wife because *"of course the women being NTs have got a lot more to say than the blokes … ah… and it is … um draining".*

Consistent with recent developments in our understanding of how women on the spectrum function socially, and discussed in the previous chapter in the context of gender roles, the women in this sample described how they role-modelled female friends or family members in order to camouflage in social situations. Models were often adopted based on qualities other than social skills that were admired and perceived to be worth emulating, as Margaret revealed:

> *"If you hang out with smarter people you keep lifting your game. Or with kinder people you will be nicer. […] And fortunately, my benchmarks have always been … you know my friend is very kind, very emotionally intelligent".* Margaret, 69 years

While the women reported knowingly using role-playing and masking as compensatory social strategies, the men did not. However, while neither Ken nor Paul explicitly acknowledged using camouflaging as a coping strategy, their descriptions of their workplace behaviour revealed it as a well-practised social behaviour that seemed to reap benefits, but also added a layer of vulnerability to their workplace experience. For Paul, "masking" was perceived as a necessary but fundamental difficulty of operating in the workplace. This was experienced as being a constant effortful endeavour to present a front – or mask – to the outside world:

> *"They [work colleagues] obviously see me as being highly intelligent, highly articulate, highly educated and they make the assumption that I would automatically always have the same capability in being considerate and social as anybody else would have … but I don't*

> *... um and I have to make a conscious effort all the time and I ... y'know, when you're tired and grumpy it can* ***slip*** *and then you just become that ... y'know, spoiled ... brat child again [laughs]".* Paul, 53 years

As detailed above, Ken found the pressures of face-to-face interaction in the workplace a "struggle". Incidental comments about his workplace experiences revealed that he consciously dealt with this by being "*someone ... you're not ... you know it's far easier*", and this seemed to afford him a sense of protection. Ken was strongly motivated by the achievement of career success, and it's possible he perceived maintaining a "work persona" – "*that's just the "me" they see"* – to be preferable to dealing with the potential professional repercussions of being himself. But this strategy in the pursuit of career goals came at a personal cost:

> *"You know I was always sort of pushing myself. I felt like I was um ... not stressed but ... I felt I was out of my comfort zone. I had to do* ***so much*** *out there interacting ... with people ...".* Ken, 66 years

There was further evidence that despite having the motivation to use varied strategies to address social difficulties, workplace or relationship success was not guaranteed, and participants' perceived problems were not necessarily solved. As Anthony's experience revealed, there always remained some instinctive element necessary for success that he could not quite account for or grasp:

> *"...thinking look if I do enough* ***stuff*** *... that will get me more points...And that should be alright...And it's not. That's my world. Getting frustrated with that because emotion's more important to them... and it gets me bizarrely riled that I can't slot that in. Y'know, I've still gotta ... it's almost like a formula... thinking if I can drop all this [social strategy] in and it all [popping sound] drops it'll all open up and it'll be right and it'll have some ... um ... uh protection around it. Because ... the ... um ... the intent is right [...] but then ... all that intention doesn't change the outcome and I'm lost with that. It's just doesn't ... marry".* Anthony, 54 years

Thus, for these participants, there were costs associated with effortful social strategies that rely on thought and planning rather than instinct, particularly if they were perceived to have failed. A range of feelings were consistently reported, from a sense of failure and frustration to emotional exhaustion, as described below:

> *"I used to think I could make people like me if I tried hard enough, you know? Therefore, if they didn't like me, it was my fault".* Anne, 69 years

> *"And [I have] figured out how I can work my world ... and then think if I work that world better… then automatically that should get better as well but it doesn't work like that and that's been my absolute ... frustration with it".* Anthony, 54 years

> *"So ... yeah I'll make it work while I'm in that space with, you know, wherever the change is ... um ... but that will just make it more challenging for me [...] and you know then it'll take me longer to recover from it. I think that's the sort of thing I'm having less and less patience with. Because it's not worth the effort, or the recovery".* Jane, 55 years

A more successful strategy was selective social interaction, or as Jane put it, "contained socialising". This was driven by a preference to only invest time in meaningful social interactions. This was a practice a number of participants adopted later in life. They described situations where once they might have persevered but would now simply avoid. Self-awareness and confidence, gained from experience, to manage situations had empowered them to not bother with trying to engage socially if they knew it wouldn't work for them, as Jane and Margaret explain:

> *"I just ... say no for my own sake. It has limited my life, but also probably um ... made it more manageable".* Jane, 55 years

> *"I don't go to parties ...haven't for years. It's just nothing I would even contemplate doing now. Not at all. [...] Once I would, but not now".* Margaret, 69 years

Similarly, participants' self-awareness and experience gave them the confidence, a form of social efficacy, to negotiate a way out of situations in which they were not comfortable, as Rose and Anne explained:

> *"One way ... actually ... to tell us ... To tell ... ah to say it, and 'sorry, I have to leave now because it's too much for me', or um just quietly sneak out [laugh]. I've done that".* Rose, 57 years

> *"You can* ***choose*** *where you go, you can* ***choose*** *who you associate with".* Anne, 69 years

Social interaction on these terms was experienced as satisfying and even pleasurable because when it did happen it had a meaningful purpose:

> *"So, I feel good about me and also feel I've had contact with another person, on my terms. It's not as stressful as normal socialising".* Jane, 55 years

6.6 Sub-Theme 6. Support

“*Moral support is important*” – Ken, 66 years

The importance of social support, particularly from family members but also from friends and work colleagues, was conveyed by all but two participants. Spouses and partners were especially helpful in providing feedback and suggesting appropriate social strategies, although there were differences in the types of support according to gender. The men in the study who had partners revealed a heavy reliance on their wives (and in one case, mother) to coordinate social engagements and interactions on their behalf, although there was a sense in some cases, such as Anthony’s, that this type of support, to provide social structure and scaffolding in social settings, was not always sought:

> *“She thinks that’s [social network] too narrow and if it’s not driven by her it falls away and she’s probably right”.* Anthony, 54 years

But typically, as in the case of John whose “*wife tries very hard to steer me along a more appropriate road [laughs]*”, the men deferred to their wives’ feedback on social skills and tried to act on it.

By contrast, spousal support from the husbands of the two married female participants was more nurturing. These women described how their husbands actively shared the load of childrearing responsibilities and household duties, and steadfastly fostered their self-confidence and self-esteem. This provided a form of social “safety net” that enabled both women to develop social efficacy; to feel confident in choosing, depending on what the situation required, to engage socially when their instinct might have been to avoid:

> *“If I was married to anyone else, I’d be divorced. Like he really is a patient man. I really couldn’t have done it without him. He’s taken, picked up a lot of slack”.* Jane, 55 years

> *“He [husband] never seen me as different, you know. I’m just me you know, and he’s always sort of loved me and built up my confidence [...] he’s never made me feel inadequate”.* Anne, 69 years

Friends and understanding colleagues were also reported as providing important lifelong support for participants. Paul described how structure in his workplace provided him with a framework within which he could safely adapt his social behaviour. Like-minded colleagues provided further support by understanding and respecting his preference for minimal out-of-work-hours socialising, and not pressuring him to engage in work social activities he was not comfortable with:

> *"But that's [my workplace] a – y'know – a very special situation. It's really quite structured and formal and all the people there are intelligent and we've got obviously a lot in common, functionally, because we're working in a team".* Paul, 53 years

Paul's disclosure of his diagnosis in the workplace, which he described as "special", suggested he had developed a sense of trust that facilitated his perception of it as a positive and supportive working environment:

> *"I th-think they got the idea. They were intelligent—perceptive enough to realise that oh [name]'s s-socially awkward and I ... have told them that I've got Asperger's so they stopped pushing it after a while and they would come to ... and maybe sometimes have a chat with me ... before they left about y'know how things were going and then they'd go off to have a drink and n-not try and push me into it".* Paul, 53 years

Only two participants, both young old males, reported a perceived lack of support, but for entirely different reasons. Ken was troubled by a perceived lack of support and understanding from his wife, particularly with respect to his preference for less socialising outside the immediate family:

> *"I've never had any help [wry laugh] […] Yeah just pushed on pretty much you know. That's my ... generally… my philosophy… just push on".* Ken, 66 years

This was a source of tension in the marriage. It was clear that Ken's worry about the potential for his marriage to collapse as a result of fundamental differences in social needs caused him additional stress in his life. He anticipated a marriage breakdown would have a range of unwanted social implications for him, including fewer opportunities for social interaction, but most particularly less time with his grandchildren who were a major source of pride and joy, and emotional comfort, to him:

> *"It'd make it more difficult for me ... I'd probably be less likely to see my grandchildren you know 'cos I'd probably just withdraw a bit, you know. That's what I predict about me. I'd have to make the effort. I would. It wouldn't be like it is now 'cos they love their Nanna ... and they love me too but… [muffled; muffled laugh]".* Ken, 66 years

There were clear disparities in social functioning, particularly social connection, across the corpus, but the most obvious discrepancy was between Charles and the rest of the participants.

Whereas the other participants were relatively socially engaged, Charles was distinctly less so; he had a strong preference for complete independence, and he did not seek or desire support from others – it was "*not something I've ever wanted*". In other ways, Charles' "social" life – his perception and experience of it – was starkly different from the other participants'. From late adolescence he had led a transient and disconnected life. His relationships with family members, particularly his parents, were fraught and finally in his 40s he cut off all contact. He reported periods of homelessness and complete social isolation, although he claimed that often this was voluntary – he would take himself "out bush and camp" because he could not "relate" to people and needed an escape. He had experienced bouts of serious ill health, hospitalisation, and attempted suicide. It seemed the lack of informal or formal support, but for that of one "friend" with whom he had maintained contact, had made Charles' life precarious. In his late 60s Charles was less settled and satisfied with life than the other participants, but according to his own measures, life had improved because he had qualified for government funded housing and financial support and was therefore released from the burden of having to conform to social – and workplace – requirements necessary to earn a living. This meant he had control over the extent to which he had to engage in "required social interactions" – still socially isolated perhaps, but in a more comfortable and habitable environment for a man nearing his 70s. Charles' "counter-case" will be discussed in more detail in Chapter 10 in Part 3 of this thesis.

6.7 Discussion

Social instinct emerged as a prominent theme incorporating seven inter-connected sub-themes that represented participants' experiences of ageing with autism from the perspective of their individual or internal world – lifelong impact, never changing, longing to belong and social sensitivities – and from an outward-facing perspective through the sub-themes of socialising as strategising and moral support. Overall, they reveal novel insights into social functioning in older adults that might help further our understanding of the developmental trajectory of autism.

Social functioning is at the core of autism, and Kanner's (1972) observations 50 years ago of the social adaptability in adulthood of some of his earliest patients is supported by the findings reported in this chapter. Indeed, Kanner described a "chronicle of gradual changes of self-concept and reactions to them along the road to social adaptation" (Kanner et al., 1972; p. 29) that presciently foreshadowed the experiences of the older adults in this study. For these participants, despite inherent and immutable social difficulties experienced across the lifespan, developing self-awareness brought with it a motivation for social adaptation and compensation, achieved through the engagement of special talents and interests, to satisfy a desire to "belong" in the social world they inhabited, either emotionally or intellectually.

The sub-themes of *lifelong difficulties* and *never changing* dovetail to provide insight into conflicting findings in the literature about the developmental trajectory of social functioning. Participants in this study reported experiencing ongoing and varied challenges with aspects of social functioning. The sense that underlying social interaction and communication difficulties had not changed throughout life was shared by all participants. Common difficulties – challenges across a range of spontaneous and unstructured social interactions and difficulties interpreting and responding appropriately to social cues; the experience of social interactions as generally effortful; and longing for and mourning a lack of deeper social connections – echoed those of other studies (Bishop-Fitzpatrick et al., 2018; Hickey et al., 2018; Müller et al., 2008) and provide further evidence of the lifelong trajectory of social functioning problems in autism.

As Müller and colleagues (2008) found, there is individual variation in the desire for social connection which is more complex and nuanced than simply being “lonely” or “not lonely”; context is important and so might be stage of life. This sample represents a cohort of older adults who very likely would not have been diagnosed as children under the earlier stricter diagnostic criteria in place at that time. Therefore, they were not exposed to formal social skills training or other interventions. But, as described and advocated for by Temple Grandin (2006), the participants in this study looked for social rules that they could learn and apply. Targeted strategies to compensate for social difficulties in ways that helped to fill perceived voids in the social side of their lives were developed and practised throughout life. Participants reported still using these strategies in older adulthood, but with age and experience came the agency to deploy them more selectively – as and when they wished after weighing up the benefits against the costs of doing so. Situational aspects of social interaction became important and participants’ primary focus in later life shifted to close emotional relationships rather than peripheral social contacts. In this sense there was a narrowing of social contacts. Contrary to indicating a lack of social connection characteristic of ageing with autism (Hickey et al., 2018) this was by choice. A novel interpretation of this might be that it is an example of the natural pruning of social networks typical of ageing more generally (Charles & Carstensen, 2010) rather than an autism-driven preference (Hickey et al., 2018) suggesting that there may be parallels between typically developing and autistic social ageing that require further investigation.

All participants in this study, with the exception of Charles, whose counter case will be discussed in more detail in Chapter 10, and to a lesser extent Paul, continued to derive informal social support from close family members or friends, including in some cases friends from early school days, into later life. These informal support networks may have been a contributing factor in their relatively engaged social activity, and supports previous findings that social factors, including attending mainstream school, may promote opportunities for exposure to social interaction "learning" which in turn might provide a grounding for continued social skill development and practice over the ensuing years (Kandalaft & deBrabander, 2021; Simonoff et al., 2020; Woodman et al., 2016).

Although participants did not directly discuss it as a deliberate strategy, compensation emerged as a social strategy. When compensatory behaviours were reported it was in an individual rather than an autism-specific context, and there were clear gender differences. For instance, contrary to other research findings (Cage et al., 2018; Hull et al., 2017), the men in this study did not explicitly report using camouflaging or masking strategies, although Ken and Paul made oblique references to masking in the workplace. It was clear both saw benefits – personally and professionally – to camouflaging, especially to suppress autistic characteristics and to blend in socially (Bradley et al., 2021; Miller et al., 2019). Their descriptions of masking in the workplace provide a brief but unique insight into male-specific camouflaging strategies that to date have been poorly understood (Bradley et al., 2021) due to the predominantly female samples used in research on this phenomenon in autism (Fombonne, 2020). By contrast, as the gender roles sub-theme revealed in Chapter 5, and consistent with the experiences of autistic women reported in other research (Bargiela et al., 2016), the women in this study, particularly Anne and Jane, reported using compensatory strategies such as role-modelling, study and copying others' behaviours in order to fit in with social peers and to conform with gender stereotypes, particularly those associated with motherhood. Jane's experience was especially similar to many others who reported finding camouflaging mentally exhausting (Bradley et al., 2021; Cage & Troxell-Whitman, 2019). However, in a novel finding, the women in this study program reported that, as they aged, they no longer felt compelled to use these strategies. Rather than being a positive consequence of diagnosis (Bradley et al., 2021) – about which Anne and Margaret were in any case ambivalent – it seems these women had reached a stage of life, and perhaps a level of self-awareness and acceptance, that brought with it a shift in social motivation and with it a freedom from feeling the need to engage in effortful social strategies.

Notably, the varying motivations and strategies reported by participants are consistent, not just with what is known about social motivation in autism (Livingston et al., 2019a), but also with social trajectories in typically developing older adults (Charles & Carstensen, 2010). All participants in this study described being more selective about social interactions in later life based on previous experience and preference. They opted out of or avoided aversive social – and therefore emotionally stressful – social situations and focused instead on activities or social interactions that were meaningful to them in the same way typically developing older adults do (Carstensen et al., 2003). This approach to social engagement is known to be associated with higher levels of positive emotions and may explain the downward trend in social stress and anxiety in older autistic adults found in this research and other studies (Lever & Geurts, 2018; Mason et al., 2019; Uljarević et al., 2019; Yarar et al., 2022). The experiences of the participants also confirm that social motivation in autism is highly heterogeneous.

In conclusion, maintaining social connection and social satisfaction in later life has been identified as a unique challenge for older autistic adults but is an aspect of life that has received little research attention (Sonido et al., 2020). The findings presented in this chapter go some way to addressing this gap by describing the life experiences of a relatively homogenous group of older adults who, despite acknowledging ongoing difficulties with social interaction, nonetheless have forged meaningful and close emotional and social connections throughout life and maintained them into later life. Social functioning across the corpus was characterised as problematic but nonetheless there was motivation to adapt to the social world. All participants exhibited, albeit with varying degrees of success, self-determination and social self-efficacy in pursuit of identified social goals, and identified weaknesses in social abilities were selectively compensated for by harnessing perceived strengths. Most participants also reported changes in their preferences for social interaction, favouring time spent enjoying solitude or with family and lifelong close friends. These characteristics have received little attention in autism studies, but many are integral to lifespan developmental models, suggesting that perhaps insights and a deeper understanding of the developmental trajectory of social functioning in autism across the lifespan, and in later life, might be achieved by exploring them from a lifespan perspective.

Chapter 7: Emotional Downs and Ups

***"I can be a bit kinder to myself"* – Anne, 69 years**

The previous chapter explored themes relating to participants' experiences and perspectives of ageing in the social realm. Social relationships and networks are known to influence emotional wellbeing and so it follows that analyses revealed the overarching theme of "emotional downs and ups" about mental health problems and solutions common to all participants' experiences. This theme describes the impact and outcomes of life's difficulties with emotional functioning, through five recurrent and interrelated sub-themes: problems in the past, triggers, treatment wariness, self-regulation, and resilience set out in Table 5. A visual representation of the interaction between these sub-themes is set out in a thematic map in Figure 4 at the end of this chapter.

Table 5

Emotional Downs and Ups Sub-Themes and Illustrative Quotes

Sub-theme	Illustrative quote
Problems in the past	*I had a lot of depression, a lot of anxiety*
Triggers	*I think I was just down because I couldn't cope*
Treatment wariness	*The doctor doesn't listen to a single word I say*
Self-regulation	*I call it getting a grip on the inside of your head*
Regrets and Self-blame	*I sometimes wonder if I am to blame*
Resilience	*You. Just. Keep. Going.*

7.1 Sub-Theme 1. Problems in the Past

***"I had a lot of depression, a lot of anxiety"* – Paul, 53 years**

When asked directly about their experiences with mental health issues, difficulties were initially reported by half of the participants. All those who did not report having experienced problems with mental health were male and, with the exception of Anthony, were in the young old age category. However, during further questioning, three of these males, John, Doug and Charles, revealed having experienced significant difficulties with mental health throughout their lifetime, including psychological breakdowns resulting in periods of hospitalisation. In all cases where mental health issues were acknowledged by participants, they referred to difficulties with co-morbid anxiety and depression.

The implications of mental health problems were perceived by participants to have had a major and negative impact on their lives both in terms of functioning generally and in the workplace:

> *"I think the effect is mostly socially. And it has affected also my ability to do more than ... just work in this sort of work, behind the scenes in [workplace]".* Rose, 57 years

Participants described having experienced mental health problems since their teenage years, but not understanding at the time what it was they were going through. Recovery was slow and lengthy for most participants, particularly for those who had suffered depression:

> *"Well, when you get that sort of thing it takes a long time to actually get over it, so it'd been building up for quite a while before it crumbled. Um. I'd say for about a year before it crumbled it'd been building, and it took several years to sort of get through that and get my life reasonably on track".* John, 74 years

Improvement in their mental health as they grew older was experienced by seven of the participants such that they felt less troubled by anxiety and depression in the present than they had in the past:

> *"Yeah d-depression is something that has changed definitely. Um I plunged into depression at puberty, I would say and was… had really quite ... severe reactive depression through my teens and certainly the university years and the few years afterwards and then ... it gradually started dissipating – again. Um ... these days ... I only get ... I'd say brief ... periods an' not severe ... depression".* Paul, 53 years

However, for those participants who acknowledged ongoing struggles with mental health, such as Paul and Anne, implicit in the way they talked about it was an acceptance that it was an intrinsic feature of life. Indeed, in Anne's case her current level of anxiety was rationalised as a "normal amount".

Nonetheless, for two participants, Jane and Charles, persistent low mood was still a feature of their lives, and both conveyed continuing feelings of hopelessness. Although Jane joked that she "wouldn't plan a suicide" this flippancy seemed to be an attempt to light-heartedly gloss over a somewhat pervasive bleakness that left her feeling *"...not that fussed on, you know, continuing to function"*. Charles was emphatic that at times living life felt like a test of endurance. He had experienced persistent suicidality since his teenage years, and had attempted suicide twice in middle age followed by extended periods of hospitalisation:

> *"So all through my life I've found that the feeling of 'that's it, I'd just like to see the end of it', has been repetitive and recurrent. But I never took action on it ... or never even thought about taking action on it, until fairly recently".* Charles, 67 years

The male participants in this study were less likely to endorse experiences of mental health issues, yet several of them referred to instances in their lives which suggested otherwise. However, through either lack of insight and awareness, or perceived concerns about the social stigma associated with mental health issues, they had not sought or received professional help:

> *"I don't think I've ever had [anxiety] and even now I'm not sure I'm depressed, you know. [Wife] would probably say I am you know ... maybe I am ... but I don't like the label, you know".* Ken, 66 years

This lack of faith in his own insight, coupled with a negative perception of mental illness, complicated and added to Ken's sense of emotional burden. Lack of insight, in particular, was clearly evident in the difficulty three male participants still had in distinguishing and describing internal experiences and emotions and is suggestive of alexithymia. Although they were aware of and could describe physical sensations related to elevated physiological arousal, there seemed to be an inability to connect these sensations to, or indeed name, the associated emotion experienced:

> *"Anxiety's too strong a term ... um heightened awareness".* Anthony, 54 years

> *"So whether it was stress ... I don't really know because ... I... maybe I'm just denying the stress or can't recognise the symptoms or something".* Doug, 69 years

7.2 Sub-Theme 2. Triggers

***"I think I was just down because I couldn't cope"* – Anne, 69 years**

This sub-theme relates to events and experiences identified as triggers of stress or mental health problems experienced by participants. Employment issues, relationships, particularly within the family, and life transitions were the most commonly cited. Workplace challenges had a significant impact on all participants. A range of employment difficulties, including seeking new work, job interviews, changes in roles and responsibilities, over-work and poor workplace relationships and conflicts were reported as triggers. While some participants managed these issues through disclosure of their diagnosis and subsequent role negotiation, this was not an option for those unaware of their autism, and in most cases their career progress was limited or came at a personal cost emotionally:

> *"The situation of ... um being in temporary employment has been a major sense of anxiety for me. [...] And I know that um ... if I am lucky to get an interview ... I get all the y'know th-the anxiety, the physical anxiety".* Paul, 53 years

Conflict between and blurring of family and workplace stressors also triggered emotional stress and, in some cases, emotional breakdown and hospitalisation:

> *"This [workplace stress] started interfering in my relationship with my wife which probably I even felt was even bigger issue because you know my marriage was so important to me and the fact that my marriage was going through a bad time because of it was really hurtful and I found it really difficult to cope with that".* John, 74 years

Indeed, relationship difficulties involving partners triggered stress and a sense of being overwhelmed for the male participants in particular. A perceived failure to meet the emotional needs of their partners was common and invariably resulted in feelings of helplessness and failure and, at times, resentment and frustration, as described by Ken:

> *"I do feel that I don't always get the recognition. Like with the list of [wife's] "don't's" I feel as if ... I knock one over and another one jumps up in its place. I feel like it's a never-ending list you know and I'm never ... ever got a never-ending list of things I need to change".* Ken, 66 years

For two of the mothers, Margaret and Anne, family responsibilities combined with other stressors, including domestic violence, triggered severe depression. Margaret experienced an unhappy marriage to a man who "*had a shocking temper and was violent*". For Anne, who had endured fraught family relationships including sexual abuse as a girl, the perceived impact of her autism on her own children was an additional trigger for her depression:

> *"I got another double-whammy of being depressed when I realised I'd passed ... I was Aspie and I'd passed it on to the kids".* Anne, 69 years

For other participants change generally was a stressor. Unexpected change in everyday situations could still bring on an "anxiety attack" for Rose, whereas for others the change was associated with something that had been a significant life focus, was integral to their self-identity or required a shift in thinking or behaviour. In the case of Doug, for whom aspects of work constituted a special interest, workplace change triggered a breakdown, stress leave from work, and eventually early retirement:

> *"We got a new [manager] at work and he was changing things that were going against the ... what the requirements were for changing things ... he didn't go through the right procedure [...] and ... and I ended up off with stress".* Doug, 69 years

Life stage transitions also triggered significant mental health difficulties for some participants. For Anne, whose adult self-identity and focus were grounded in a traditional motherhood role and the responsibilities of her family, the transition to an "empty nest" brought about a change in her daily routine and, perhaps more distressingly, in her sense of purpose and meaning. She was completely unprepared emotionally for this new stage in her life, and it triggered a relapse of her depression:

> *"I don't know; it was just this ... it was just this one thing I realised that was my focus. And that was raising these [children] and being a good wife, and it was like I was ... yeah I couldn't I couldn't handle the ... 'cause I hadn't imagined what it would be like, you know?".* Anne, 69 years

As discussed in Chapters 5 and 6, the adoption of traditional gender roles, such as daughter, wife and mother, was something that all the female participants engaged in, with varying degrees of success, throughout life, and for all of them this strategy took a considerable emotional toll. The focused effort required to understand and conform to the social expectations of these roles combined with the pressures associated with years of masking, copying and pretending in order to fit in – and the sense of failure when it all became too overwhelming – was confidence-sapping and stressful:

> *"So I just feel like I've been a damn fine actress and that to do anything that anyone else does and like things that Mum has always expected, you know, the family ... costs me so much more ... that ... um ... you know just to function in a day ...".* Jane, 55 years

The male participants did not report feeling the same pressures to camouflage or role play in order to blend in socially, however their perception, and possibly that of others', of themselves as "*different*", "*weird*" or "*not a blokey bloke*" (John) brought with it other triggers of emotional pain, such as social exclusion and isolation, common to autistic experience and certainly a negative experience for John and Paul in particular at earlier stages of life.

7.3 Sub-Theme 3. Treatment Wariness

***"The doctor doesn't listen to a single word I say"* – Charles, 67 years**

All participants had experienced mental health difficulties ranging from high levels of stress to anxiety and depression requiring hospitalisation, and with the exception of Ken and Anthony all had received medical treatment. At a broader level, all participants had sought medical or allied health intervention, including from psychiatrists, psychologists, counselling therapists and general practitioners (GPs) for mental health, social, relationship and autism-specific issues. Five participants had undergone formal diagnostic assessments for autism prior to their participation in the study. Nonetheless, despite a degree of familiarity with various forms of treatment and interventions, there was a distinct theme of distrust and disdain for most forms of treatment and, to a lesser extent, health professionals, particularly medical doctors.

Many participants recounted examples of consultations with medical practitioners and other health professionals in which they felt they were not listened to, and their concerns were not adequately explored or addressed. In Ken's case, a visit to his general practitioner (GP) was a desperate attempt to find support and reassurance as he grappled with low mood triggered by relationship difficulties with his wife which in turn were driven by issues she attributed to Ken's undiagnosed autism, a label he was deeply ambivalent about:

> *"I said, 'I think I've got Asperger's or something ... my wife thinks I've got Asperger's. She said I'm depressed', you know. He [GP] said 'Oh ...'. He said, 'Well, if you are it's too late to do anything about it', and secondly, on the depression, he said, 'No, no', he said, 'you don't present that way at all'".* Ken, 66 years

This inadequate response exacerbated Ken's feelings of emotional vulnerability and confusion. It was compounded by his experience with autism-specific health professionals who he felt either too quickly categorised him or unfairly judged and mis-represented him:

> *"[ASC-specific couples' therapist] said I was trivialising [wife's] anger and I don't feel I do trivialise her anger. I feel I do try to respond. But ... um ... so ... There's certainly an element of truth but I thought it made me appear quite violent in the group, you know. So, I felt a little bit um ... mis-represented you know, and I was going to send an email saying so and I wrote it, but I never sent it ... But I thought look ... it ain't worth it, you know. It ain't worth it".* Ken, 66 years

As a result, Ken felt he was not heard; his perspective was not valued, and health professionals were more focused on the autistic part of him than understanding the essence of who he was as a unique individual. For Ken, the best alternative was to say nothing at all than to risk placing his trust in the group process or the therapist, thus reinforcing his perception that his perspective was not valued or deemed valid.

Most participants had similar encounters with health professionals and, as a consequence of their general distrust of doctors, there was a preference to avoid medical treatment if possible. Perhaps the most extreme version of this was Charles' scathing lack of regard or trust for the medical profession:

> *"I have been aware for many year – decades, in fact – that according to medical beliefs, persons such as myself do not – cannot – exist. In this view, the experiences I recount are either conflations of mundane events or mere imaginings, the beliefs I espouse are delusions, my persisting in them indicative of the need for psychiatric counselling, and my refusal proof of a need for treatment and (hopefully) a long course of (highly profitable) medication".* Charles, 67 years

A number of participants stressed their view that treatment was not worthwhile unless it was tailored to an individual's unique needs and circumstances. Ken's bruising experiences crystallised this view. Like Ken, in terms of treatment, all participants saw their autism as just one, relatively recent, part of their identity, and not the only factor – but certainly a complicating one – in the mental health and social issues and pressures they experienced in later life:

> *"And um ... if you're going to really help someone you need to understand a bit more about them. [...] You need to understand. You probably do need individualised therapy because you need to be able to um ... get an understanding of all the things that contribute to getting you from 'a' to where you are now you know. Like ... and Asperger's is just one of them".* Ken, 66 years

An aversion to drugs was also a common theme. Some participants had been prescribed medication for anxiety or depression but found them either unhelpful or the side-effects off-putting.

> *"I was still on a lot of anti-depressants and anti-anxiety drugs, so I was a bit of a bit of a zombie [...] and it was affecting my parenting and all that sort of thing".* Anne, 69 years

Other participants, such as Charles and Jane, simply refused to take medication, despite their doctors' recommendations. In both Margaret's and Jane's cases concern about taking medication was, like Anne's experience, informed by their responsibilities as mothers. However, Jane faced a scenario where, on the basis of her refusal to agree to take prescribed medication, she was denied further treatment:

> *"She sent me off to see a psychiatrist and he told me … gave me anti-depressants and I said well, a. I don't think I'm depressed, b. I'm still breastfeeding, and c. you know, can we not talk about this? And he said if I wouldn't take the antidepressants there was no point me seeing him. So that was the end of our visits. I didn't take the antidepressants [laughs]".* Jane, 55 years

Thus, all three women sacrificed, in various ways, their own wellbeing in favour of their roles as mothers with a sense of helplessness and resignation that *"there was actually no one to talk to"* (Margaret) in a meaningful and supportive way about treatment for their mental health.

The elapse of time and a preference to "*naturally medicate*" (Anthony) was endorsed by most participants and, like John, drawing on their previous experiences with anxiety and depression, they self-monitored and "treated" themselves accordingly:

> *"You know sometimes I go back on St John's Wort or something like that to sort of pull myself back a bit, you know".* John, 69 years

Difficulties with communication are a fundamental characteristic of autism, however good communication is fundamental to any therapeutic relationship, regardless of the inherent skills or abilities of the patient. At the most basic level, practitioners' failure to ask "*piercing questions*" (Margaret, 69 years) of participants in this study contributed to a generally negative view of health professionals and the belief that personalised professional support was not something they could expect or rely on. As they reach a stage of life where other health issues may start to emerge, this wariness of the medical profession is troubling:

> *"To date I have succeeded in avoiding or escaping such attentions, although in recent years I've fallen prey to physical infirmities that I've survived thus far with minimal consequences (touch wood)".* Charles, 67 years

Participants' experiences suggest the consequences of treatment wariness have not been minimal, and a strategy of avoiding health professionals and treatments, much less continuing to rely on luck, does not bode well for emotional or physical wellbeing in later life.

7.4 Sub-Theme 4. Self-Regulation

***"I call it getting a grip on the inside of your head"* – Margaret, 69 years**

Associated with the sub-theme of Treatment was the sub-theme of Self-regulation. Throughout the data distinct patterns in attitude and behaviour, developed by participants over the course of the lifespan to manage their emotions, were identified. Having experienced the negative consequences of poor emotion regulation, and in some cases the depths of emotional distress, earlier in life most participants expressed a strong motivation to avoid doing so again. As Margaret explained:

> *"I decided it [depressive episode] couldn't happen again. I mean ... if you actually got to the bottom of that pit, you couldn't go back there again".* Margaret, 69 years

Since for most participants professional help was not seen as a therapeutic option, alternative self-regulatory strategies were actively employed to regulate emotions. Some of these were maladaptive practices, but most were positive.

"Meltdowns", intense reactions to stress that are sometimes expressed as violent or uncontrollable outbursts – described by Margaret as like going "*off like a packet of crackers*" – are a common example of maladaptive emotional regulation in autism. However only four participants, Doug, Charles, Paul and Margaret referred explicitly to continuing to experience emotional outbursts into later life. Doug, Paul and Margaret had developed an awareness of the triggers and warning signs of their meltdowns in order to better manage them – they recognised they were unhelpful, a source of difficulty, particularly in semi-professional and workplace situations, and unpleasant for the people around them. But all acknowledged they continued to have difficulty controlling them, which in itself was stressful.

Both Doug and Charles also talked about their use of alcohol to manage emotions. Doug's "*couple of scotches before going to bed*" were a way of "*fighting stress*" and "*to numb*", but there were rules about his alcohol intake – "*never drink any alcohol during the day*" – and as he has aged, he relies on it less. However, for Charles meltdowns, alcohol, and occasional cannabis use typically go hand-in-hand, albeit infrequently, at periods of desperation (e.g., loss of employment, poor living conditions) in his life. At times these episodes have been extreme and triggered periods of prolonged mental and physical ill health resulting in hospitalisation and thus perpetuating a cycle of feelings of hopelessness and futility. Charles experienced cycles of extreme highs and lows and made two suicide attempts. However, with an extremely suspicious attitude to health professionals, who he perceived as "*No help at all. Absolutely no help",* the likelihood of him seeking, much less receiving, appropriate treatment is greatly reduced and the cyclical pattern of ups and downs is likely to continue. The culmination of Charles' lifetime of experiences and lack of insight, are representative of how easily a range of emotional regulation difficulties, exacerbated by social isolation, can perpetuate poor outcomes for autistic adults into later life. At other times, however, Charles' managed overwhelming emotions more adaptively by engaging in meditation which he found "*inspires ideas across the next weeks and months*".

However, all the other participants revealed that with the benefit of self-awareness and life experience, they had developed and routinely practised various healthy strategies to monitor their emotions and maintain good mental health:

> *"Since I had a major breakdown, I've been very aware of where I'm at emotionally and mentally, so I've been extremely aware of where I am and very sensitive to it".* John, 69 years

In most cases participants came up with these self-regulatory strategies themselves through reading and experimentation, rather than on the advice of health professionals or others. While Paul used stimming, a repetitive physical movement used by some autistic individuals as a calming technique, that he found soothing as a child was a positive way to self-regulate (he described it as one of his "Aspergery", "bizarre" behaviours and for him engaging in it was contingent on his ability to live independently) for others adapting their intellect to addressing negative tendencies had evolved over time. For all participants there was a strong emphasis on the power of the mind in managing emotions. Implicit in this was that negative thoughts were perceived as problematic and coping with them required cognitive control *"to change your mind"* (Ken), *"empty your mind"* (Charles), *"let the thoughts pass"* (Rose), or to *"work it out"* (Anthony) and in doing so achieve a sense of release and calm. For instance, Margaret learned and practised deliberate mental self-control to avoid ruminating. She had recognised as a child, and then again in later life, that ruminating on stressful experiences had a negative impact on her mental wellbeing and resolved to stop doing it:

> *"I was probably about 50 actually and [had] a big interchange at work one Friday with this cow of a woman and went home for the weekend and thought how on earth can I cope with this by myself for the weekend ... and ... I'd read in the meantime that rumination ... yeah well should never have forgotten that trick. Just don't think about it.* ***Refuse*** *to think about it. And I* ***refused*** *to think about it. So, by Monday when I let myself look at it ... I discovered something [smiling]; I discovered it wasn't so bad after all. I'd had 48 hours* ***off****. It was good. It was good".* Margaret, 69 years

Other cognitive techniques, such as positive self-talk, were also used by several participants:

> *"So I used to try and sort of gee myself up and say 'Oh, come on, for goodness sake', you know, 'you can manage this', and all that sort of thing, you know".* Anne, 69 years

Mindfulness, meditation, spiritual and physical activities, such as gardening, were consistently mentioned as successful techniques for self-regulation. These activities, and sometimes a combination of them, were typically enjoyed as calming solitary pursuits that had developed over the life span to become a key strategy in self-regulation, and were cited by several participants as important to helping them to achieve a sense of peace and emotional stability without the negative side-effects of medication:

> *"If I find myself as I do at times getting emotionally keyed up … like … you know I decide I've gotta get out of this place … shooo how do I do it? … then you sit down, you meditate, you deliberately … there are certain techniques you can use to just empty your mind of thoughts".* Charles, 67 years

> *"Even like when I walk these days, I like to walk on my own because I find it meditative you know, always have done […] Running and that you know. Always found it calming".* Ken, 66 years

Fundamental to the success of all these coping strategies was participants' ability to proactively adapt both instinctive and learned behaviours, developed and practised over the course of the lifespan, to regulate their emotions. Notably, autistic preference for routine and repetitive and restrictive-like behaviours, demonstrated by Paul's preference for stimming, were harnessed by participants in an adaptive way through other physical activities such as running, swimming, and gardening to regulate emotions. Evidence-based psychological techniques such as cognitive behaviour therapy and mindfulness were also intuitively and intellectually adapted. These creative approaches to self-regulating emotion in themselves are examples of positive adaptation to their environment seen in all living creatures.

7.5 Sub-Theme 5. Regrets and Self-blame

***"I sometimes wonder if I am to blame"* – Rose, 57 years**

Despite proactively monitoring and regulating their emotions, most participants nonetheless expressed regret and self-blame for the perceived impact of their autistic characteristics on their relationships and ability to fully realise their potential in life. Participants' experiences were shared with a poignancy triggered by reflections on the past which now, in later life, could be understood from a different perspective thanks to a deeper self-awareness and insight developed over the lifespan, coupled with the context of their diagnosis and recently acquired knowledge about autism.

All participants regretted not having received their autism diagnosis earlier in life, however this regret was for diverse reasons and manifested itself in different ways. For some participants there was regret for the limitations they perceived their autistic characteristics had placed on their ability to make the most of opportunities. As Anne explained:

> *"But I sort of look and I think mmmmm it's a shame I wasn't different you know [...] I could have ... I could have um maybe handled my life situation so much better if I was more, you know, aware. I just think that Asperger's in itself has been ... has limited me you know by having Asperger's it's limited me".* Anne, 69 years

For Anne, as for others, feeling a lack of personal fulfillment was complicated by regret for a perceived absence of self-awareness in the past, and the negative impact that had on relationships and social interactions. With hindsight, most participants attributed poor emotional awareness and understanding to unintentionally causing hurt or offence to others. This realisation was an additional source of sadness and dismay:

> *"I think I mighta hurt a few people on the way along just because I wasn't very um ... careful ... other people have told me that I'm tactless and I say things that are hurtful sometimes. I've never meant to hurt anybody at all".* Anne, 69 years

However, participants' remorse for past behaviours that may have "*offended*" (Margaret; Anthony) others was counter-balanced by acknowledgement that at the time they were "*oblivious*" (Paul) and "*ignorant*" (Ken) of the way their behaviours may have been perceived; they now understood these in the context of their autism and therefore beyond their control:

> *"Um.... [long pause] Too much of it [arc of the lifespan] is not the way it sh—nah ... Not good. Not good. Not good at all. But ... ummmm [tears; long pause] ... that wasn't under my control. So... and I didn't know any better".* Margaret, 69 years

Margaret articulated how nearly all the participants viewed the past. For Margaret and most other participants, grappling with a combination of mental health issues and feelings of vulnerability in close emotional relationships, coupled with a perceived sense of responsibility and regret for difficulties in relationships and a lack of skills to address them, combined to form a complex emotional burden. Self-blame and bitterness continued to be a burden for Ken who like Margaret was emotionally raw. In Ken's case this may have been due to the relative recency of his autism identification which had precipitated a late life reframing of his self-identity, and re-opened old wounds relating to relationship difficulties with his wife. As he explained during a particularly emotionally charged moment in his interview:

> *"Well I know why [partner] was [having an affair] 'cos it was my behaviours. Like it was my Aspie-like behaviours or not meeting her emotional needs"* and *"I agree with [wife] ... that she would have been happier um ... without me ... like wasting her time, wasting her life*

> *in fact. Is the way she's seen it. And I feel as if it has been ... yeah I have contributed to that waste of life. In an emotional sense. Yeah. So ... that'd make you feel down".* Ken, 66 years

However, most participants, including Ken, were able to re-frame negative memories of aspects and events in their lives and this seemed to provide them with an unexpected emotional balance, and indeed a more positive perspective on life. There was a sense that with time and life experience participants had developed a greater self-awareness and, ultimately, self-acceptance and self-forgiveness; their positive appraisal of life left less room for negative emotions such as regret as Anne revealed:

> *"I'm very glad now that I can be—you know, I've dealt with all that and I can be a bit kinder to myself and say well 'I wasn't aware of that's how I was being' but evidently ... it was the way I was, you know...". Anne, 69 years*

Only two participants, Jane and Paul, stated they felt no regret. These participants both had a strong sense of self-belief and acceptance, as Paul explained, *"But I say to people, "I'm afraid that's just how I am". That's just ... I don't regret it at all".* Both had embraced their autism diagnosis as an integral part of their identity, partly perhaps because, unlike the older participants in this study, they had actively sought answers to why they felt different from others; they were pragmatic about their pasts, and their autism, and did not feel they needed to make apologies for their younger selves:

> *"I actually don't regret things I have or haven't done cos I haven't done them mindlessly. I lived mindfully".* Jane, 55 years

7.6 Sub-Theme 6. Resilience

***"You. Just. Keep. Going"* – Margaret, 69 years**

The sub-theme of resilience was prevalent throughout the corpus of data. Throughout the interviews participants conveyed stoicism and a lack of self-pity as they each described how they managed, with persistence and determination, a lifetime of mental health issues, relationship and employment difficulties, feelings of difference and failure. The common thread throughout was neatly articulated by Rose who explained that "*finding a way to live life is important*". For these individuals this involved self-reflection and a self-motivated pursuit of lifelong learning about their abilities – and limitations – to persistently identify and test strategies for the achievement of personal, social, and professional goals. As Margaret put it:

> *"If you're not stupid and you've ... pretty good self-control ... unless something that you can't handle mentally happened [...] you just keep going".* Margaret, 69 years

Of course, the toll of this approach was that all participants did have periods of difficulty with their mental health, but even this was met with determination:

> *"I've never had any help [wry laugh] [...] Yeah just pushed on pretty much you know. That's my ... generally... my philosophy... just push on".* Ken, 66 years

> *"I always thought I was a very brave person and a stoic person. So I would just suck it up Princess and get on with things".* Jane, 55 years

Now, in later life, participants conveyed a sense that with time and life experience they had developed a degree of self-efficacy and pragmatism in managing challenges as they arose. This approach was explained by Charles:

> *"I'll simply deal with it at the time. But I see no point in anticipating or worrying or even [...] Simply have to deal with it".*

This was echoed by Margaret in relation to current physical health problems, *"... as we always have we will deal with it when it comes"*. Finally, Rose posed an interesting question in the context of her approach to life in the face of missed and mis-diagnosis, mental and physical health issues, and struggles to maintain an independent and fulfilling life:

> *"As a person with ASD I have had to fight my way through life and find a way that works for all. Can too much help render 'an ASD' more helpless than able?".* Rose, 57 years

7.7 Discussion

This is the first qualitative investigation we are aware of to examine in detail mental health experiences across the lifespan from the perspective of late-diagnosed older adults who have been able to live an independent life. While previous research has identified a possible downward trend in the prevalence of mental health problems in adults in later life compared with young and middle-adulthood (Lever & Geurts, 2016b; Uljarević et al., 2019; Yarar et al., 2022), this research program aimed to explore the personal experiences behind these findings, with particular focus on changes over time, anxiety and depression, and coping strategies. Identified sub-themes encapsulate a range of emotional experiences from the perspective of older autistic individuals, which may have implications for our understanding of ageing with autism in terms of the interplay between individual and systems-level factors, and in the context of lifespan developmental theory.

All participants reported experiencing mental health difficulties across the lifespan, particularly anxiety and depression, which is consistent with high levels of self-rated mental health problems in older autistic adults found in other studies (Roestorf et al., 2022; Tse et al., 2021; Yarar et al., 2022). However, while some participants continued to be troubled by periods of anxiety and depression, for most these periods were experienced less frequently and less intensely, reflecting a downward pattern, a paradox of ageing, similar to that seen in the general population (Carstensen et al., 2011), and previously identified in older autistic adults (Lever & Geurts, 2016b; Uljarević et al., 2019). Nonetheless, just as earlier life turning points, such as the transition to adulthood, or the move from school to university, have been highlighted as challenging and stressful for young adults on the spectrum (Lai et al., 2014), later-life transitions including retirement and changes in the family unit to an "empty nest", triggered stress, anxiety and depression for several participants in this study. Participants' unpreparedness and inability to cope with unexpected changes in their lives provides experiential context to emerging research which has identified associations between autistic characteristics, such as an insistence on sameness and preference for routines, with intolerance of uncertainty and anxiety (Hwang et al., 2019).

Previous research (Griffiths et al., 2019) has suggested autistic adults may be more vulnerable to negative life events because social and communication difficulties compromise their ability to recognise and avoid harmful situations, which in turn may be associated with the development of co-morbid mental health conditions. Participants in this study experienced a range of negative life events from victimisation in the workplace (John, Doug), sexual abuse (Anne), domestic violence (Margaret), financial hardship and homelessness (Charles) – events which they associated directly with the development of mental health problems such as depression and suicidal ideation. These experiences provide insight into how social vulnerability can lead to exploitation.

Treatment wariness is a likely contributing factor to late or missed diagnosis and treatment of mental health problems in older adults with ASC. A distinct pattern in this study was participants' distrust of health professionals who were perceived to lack awareness and understanding or willingness to provide individualised treatment. Inadequate access to support services has been identified as a factor in lower quality of life for older adults on the spectrum (Mason et al., 2018). A disparity in the availability, quality and use of ASC-specific services has been noted in previous research (Lord et al., 2018) and if there is also a distrust and avoidance of services as reported in this study, this presents a chicken-and-egg type problem in terms of ensuring older adults seek and receive the support and treatment they require. An extension of this distrust, and a novel finding, was participants' strong aversion to medication and preference for natural remedies. In most cases antipathy for medication was long-standing and exacerbated by perceptions that over the years concerns about its impact and efficacy were not heeded by health professionals.

The results of this study program also provide support for the notion that mental health problems in older adults with ASC may be further complicated, as research suggests it is for young and middle-aged adults (Maisel et al., 2016; Robertson et al., 2018), by a lack of insight, which manifests as an inability to identify and communicate internal emotional experiences. Evidence suggests that alexithymia is common in individuals with autism and may be a predictor of anxiety, possibly because difficulty in identifying or describing emotions becomes frustrating and overwhelming (Maisel et al., 2016). Several of the males in this sample perceived stress or anxiety in terms of physiological indicators, and did not make the connection between these sensations and negative emotions despite previous experiences of mental health difficulties. This inability resulted in missed or delayed opportunities for treatment until, in some cases, hospitalisation was required.

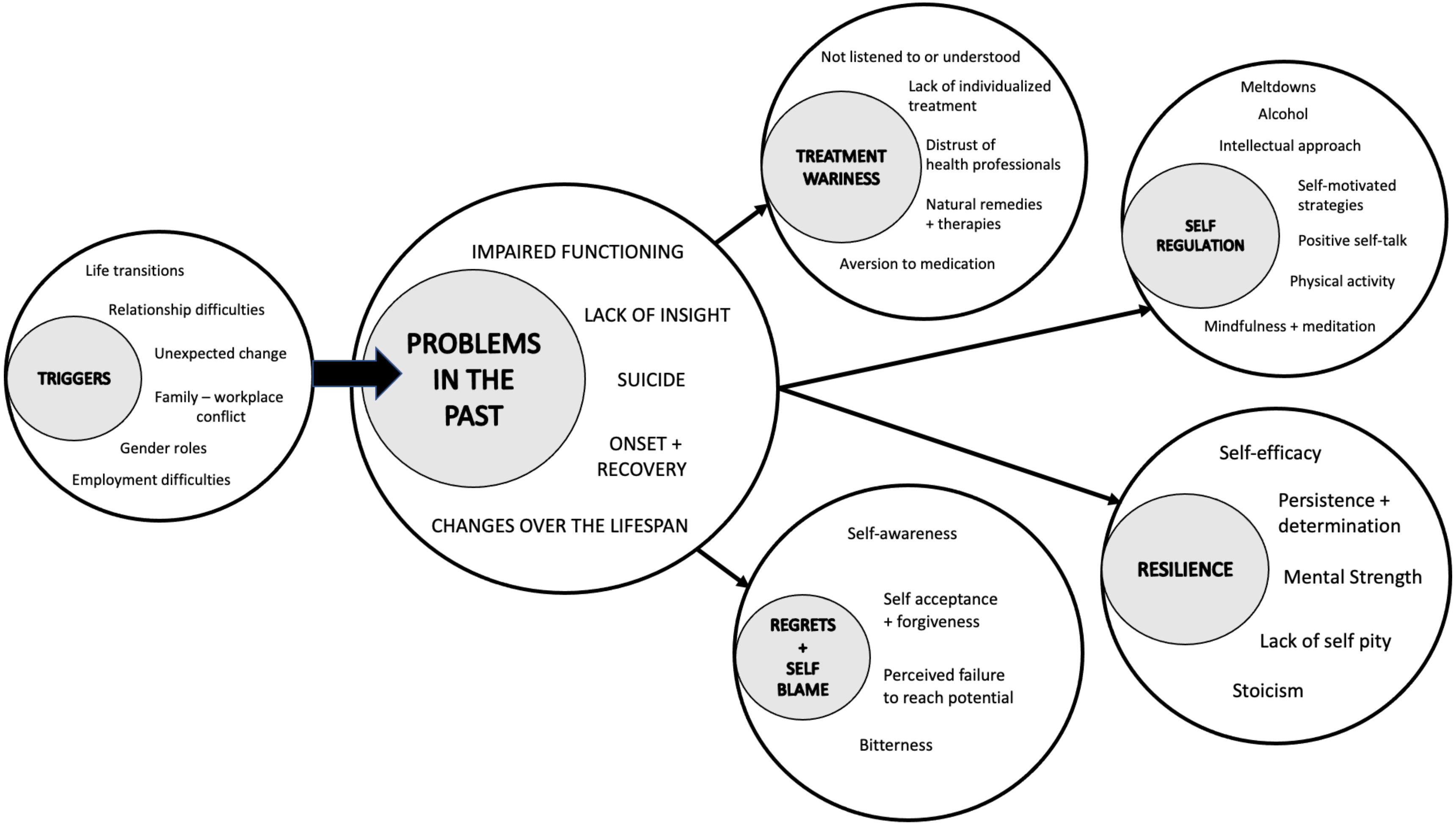
Participants also described how experience gained with the passing of time had brought improved self-awareness and greater self-acceptance in later life. Participants' self-acceptance allowed them to be less critical of themselves and was achieved by reframing perceived past failings, and limitations in the present, as integral to their autism and therefore beyond their control. Previous qualitative research into middle-aged to older autistic adults (Hickey et al., 2018; Robertson et al., 2018) has identified a similar pattern of self-awareness and self-acceptance after later-life diagnosis. The significance of self-acceptance in older adults can be considered in terms of emotion regulation. For instance, a number of the participants in this study preferred to engage in self-regulatory techniques such as mindfulness and meditation which require and enhance acceptance and may play a role in reducing negative emotions. Maisel et al.. (2016) suggest acceptance-based therapies assist people with ASC to attend to negative thoughts and feelings in the present without judgement, thus encouraging emotional acceptance and potentially alleviating anxiety. Self-acceptance in typically developing older adults is associated with successful ageing and promotes longevity (Ng et al., 2020), and it would be useful to explore the possibility that a relationship between self-acceptance, emotional acceptance, and mindfulness therapies might enhance emotional wellbeing in later life for autistic individuals too.

Despite reporting a lifetime of struggles with mental health and other socioemotional difficulties and vulnerabilities associated with autism, resilience characterised the experiences of all participants in this project. The role of resilience in the mental health of individuals on the autism spectrum is yet another relatively unexplored topic (Szatmari, 2018), although late-diagnosed women with autism believed it had aided them in negotiating life's difficulties before and after diagnosis (Leedham et al., 2019). There is a strong association between resilience and self-rated successful ageing in the general population (Jeste et al., 2013), and given its prominence in the current project, the potential benefits of this trait to successful ageing in autism warrants further research. In particular, it would be useful to understand whether resilience is prevalent in other samples of older autistic adults or a trait peculiar to this corpus of adults. Either way, drawing on what is known about resilience in the typically developing population, an examination of which individual characteristics and systemic factors in autistic adults correlate with better-than-expected outcomes might inform the development of more targeted support and treatment programs in childhood and adulthood.

In conclusion, this chapter provides depth of insight and highlights the similarities and differences of emotional downs and ups experienced by older adults with ASC, particularly in relation to mental health problems over the course of the lifespan. Despite difficulties these participants' stories reveal some potentially positive aspects to ageing on the autism spectrum. Through a lifetime of trial and error, the adoption of adaptive emotion regulation strategies, and the development of resilience and self-acceptance, it seems that older autistic adults experience developmental gains in later life similar to those seen in the typically developing population. The results also have some important clinical implications. Firstly, they reinforce the need, already highlighted in previous chapters, for increased awareness amongst health professionals to ensure lifelong developmental conditions such as autism and associated mental health problems in older adults are understood and routinely screened for. Secondly, improved delivery of healthcare and treatment interventions that take account of social and communication differences and difficulties characteristic of autism are needed and, finally, exploration of the efficacy of mindful acceptance-based therapies and self-regulating strategies rather than medical treatments is warranted for autistic older adults with mental health issues.

Figure 4

Thematic Map of The Interaction Between the Sub-Themes Within the Overarching Theme of Emotional Downs and Ups



Chapter 8: Poignancy and Positivity

***"Life's good now"* – Anne, 69 years**

This theme explores the relatively positive outlook on life conveyed by participants throughout their interviews. Participants' poignant reflections revealed sub-themes of *independence and autonomy*, *awareness and acceptance*, *positive-reframing* and *contentment* and — perhaps surprisingly — *humour*.

Table 6

Poignancy and Positivity Sub-Themes and Illustrative Quotes

Sub-theme	Illustrative quote
Independence and autonomy	*I really only want to, y'know, do my own thing*
Awareness and acceptance	*I think I've become more friends with myself*
Positive reframing	*It's no good looking back and saying oh I did that badly*
Contentment	*I'm quite happy doing what I'm doing, actually*
Family	*The family is obviously extremely important to me*
Humour	*Ha ha [laughs] It's funny, but it's sad ... yeah*

8.1 Sub-Theme 1. Independence and Autonomy

***"I really only want to do my own thing"* – Paul, 53 years**

Participants reported feeling that older age had granted them greater independence and autonomy, a sense that "*nobody's standing over me"* (Margaret, 69 years). For Paul gaining independence was something he had worked hard to achieve; it was a positive aspect of older age that represented both achievement of personal goals and freedom:

> *"The fact that ... life is ... more bearable for me w-w- partly because of self-knowledge but also because I own my own house and I'm able to live … the isolated life that I need … um rather than being forced to be cheek by jowl with other people even in my ... off hours, my private time".* Paul, 53 years

For some participants, the notion of independence was tied to concepts of personal responsibility and control. As Margaret put it, "*I'm responsible for my own actions"*. Success in achieving independence on these terms was conceived as winning a battle and seemed to benefit self-esteem. But there was recognition that independence and autonomy, while prized, could come at a cost. For most, like Rose, this was a trade-off that was worth making:

> *"It is also my pride and self-respect to consider. If I always will need help I have lost! I **must function** alone, do things alone even if it ruins my health for days afterwards".* Rose, 57 years

Rose also alluded to emotional independence as a form of defence which was represented by a preference to avoid partner or romantic relationships. Like Charles, Rose was generally more guarded in relationships and revealed some resentment towards her immediate family who still made life decisions on her behalf. Forging an independent life away from them was important to Rose's sense of autonomy and self-esteem.

Only Jane, in the middle-aged group, reported experiencing less independence (and greater dependency on her husband) as she got older. Moreover, Jane, like Rose and Paul who were also in the same age band, was fearful that increasing age and frailty might lead to the need to move to a care home which she associated with loss of independence:

> *"I don't want to be dependent on the doctor. At all. That's ... that's hard for me. Hmm. Um. And being in an aged-care facility. That would... not be good".* Jane, 55 years

Rose had a different, albeit mixed, perspective on aged care. With humour she commented that there could be some benefits at the institutional level because "*people with Asperger and autism would be the perfect patients in a ... old homes, elderly people's home because* [there is] *always a routine and we love a routine".* But at a personal level, it was an eventuality that she feared, possibly as a carryover of past negative experiences with health professionals whose failure to understand her had resulted in sub-optimal care:

> *"I **think** I will fear not being able to cope and not being understood and treated ... and have it treated like er ... like something else. Because people don't understand".* Rose, 57 years

A driving force in Paul's life was his motivation to achieve an independence in his living arrangements that afforded him physical as well as mental space. He perceived ageing as a potential threat to that life goal and to his mental wellbeing. As he explained:

> *"I really hope to be able to … live an independent life. It's my big aim in life and [breath] it's just for my mental health I need to live alone".* Paul, 53 years

Interestingly, specific concerns about the erosion of independence with age were only raised by participants in the "middle aged" age category. The older participants framed independence positively, and in terms of the present rather than concerns for the future. As John succinctly described it, "*I'm coping quite happily independently".*

8.2 Sub-Theme 2. Awareness and Acceptance

***"I think I've become more friends with myself"* – Rose, 57 years**

Although self-awareness was a feature in terms of developing successful social strategies and emotion regulation, it emerged as a critical factor in participants' perceptions of the benefits of later life. Participants discussed how they had reached a stage in life where they felt comfortable with who they were. Through awareness and self-acceptance they were able to view their autism, or "difference", and life in general more positively:

> *"I think just having a realisation that I do have AS and I must admit I do try and not let it interfere with my life. That's not always successful by a long chalk. I understand that. But I think it's probably just the realisation that I do have this surprising thing in my life can be useful in understanding some of my grandchildren and other people. I think it's become easier over time".* John, 74

For Anne, self-acceptance was nuanced; it seemed to be more for *herself*, and somehow separate from her autistic self about which she conveyed some ambivalence. In achieving self-acceptance in later life, Anne relieved herself of a lifelong inclination to compare herself to "*everybody else*":

> *"I think it's that* ***I've*** *become more accepting of* **myself** *– you know … weird ways, you know? […] And it doesn't matter anymore and … you know and I think that's a bit … and so consequently I'm OK with everybody else".* Anne, 69 years

For some participants, such as Margaret, their self-awareness and acceptance allowed them to embrace new and rewarding activities, such as volunteer work and participating in community groups, more fully and in doing so to appreciate themselves and life more than they had in the past:

> *"Kind of finally realising, coming to terms with myself and the fact that … ummm…. I'm not that bad…ummm and I've been able to be useful… but the other thing, one of the things*

> *about [volunteer work] is that ... 'cos volunteer work always gives you more than ... than you give".* Margaret, 69 years

Awareness garnered from life experience and an acceptance of personal limits – *"how to do those things with your limitations"* – enabled Rose to negotiate work schedules that suited her and enabled her to find joy in her work without, as Anne and Margaret experienced, worrying about negative judgement from others:

> *"It's become more enjoyable because I learn ... Ok, I can handle this, but not this. So I shy away from the things I can't handle. I'm ... just thinking practically, OK, I can work 40%. If I work 50, I bite ... on Fridays. If I work 40, I don't work on Fridays and have a nice life. So OK, I accept it".* Rose, 57 years

Although Jane was also aware and accepting of her autism – as she put it, she was "*being more "me" as I get older*" – her reflections conveyed that she was also experiencing a period in life of greater emotional intensity that cycled through sadness, anger, and laughter. Jane's outlook was distinctly less positive than that of the other participants, and she clearly felt extremely emotionally exhausted. As a 55 year old woman, it is possible that these emotional fluctuations were a part of menopausal transition, although this was not a topic raised by Jane. Nonetheless, there was a sense that Jane's self-acceptance involved letting go of "*the virtual mask [that] has just got too ... exhausting to keep up*". She noted that, "*the older I've got the less I'm prepared to play games*", and instead her focus had shifted to what was important to her, rather than the expectations of others:

> *"Pretty much every serious decision ... um ... I try to do it independently. Not 'Oh, what will people think?' or 'What will they say' or 'Everyone else is doing that'. [But], 'What's best for me, or for us? How our family works?'"* Jane, 55 years

By contrast, a clear counter case was Anthony, but not because he was struggling to come to terms with his life experiences. Rather, he had a strong sense of self identity and positive self-esteem which he had carried throughout his life. The concept of "self-acceptance" was not new to him but had always been a feature of his identity and he was quite clear that "*If I had my time again, I would not be anyone else*".

8.3 Sub-Theme 3. Positive Reframing

"It's no good looking back and saying 'Oh, I did that badly'" **– Anne, 69 years**

Awareness and self-acceptance, and acceptance of the influence of autism on their lives, seemed to allow participants to re-frame their life experiences in a pragmatic but also more positive light. This involved focusing on the positive aspects of life, both separate from and because of their autistic characteristics, rather than dwelling on just the negatives, and all participants revealed examples of this. For instance, Doug explained how now he re-framed differences that had caused social difficulties in the past as "*the Aspie part of me that's not fitting in".* Despite some past difficulties in his marriage, John reflected that *"we're coming up to being married 50 years so it can't be that bad [laughs]".* Even Charles, for whom, by his own measure, life was still in some respects relatively precarious and unanchored cast himself, at least in the moment of the interview, as feeling "*very lucky in many ways, I've survived, I'm still in robust health ... I've ... some of the things I've been through you wouldn't believe. I'm lucky to be here".*

A propensity to mindfully reflect on situations and re-frame them in a positive light; to celebrate successes rather than chiding themselves for, or being upset by, perceived mistakes or social faux pas was common across the corpus. Anne described this reflective process as one she deliberately engaged in to balance or counter negative perceptions:

> *"I really, really need time on my own [...] to be able to keep processing everything really. And not being too hard on myself. It's no good looking back and saying oh I did that badly, that badly ... I'm sort of thinking well you know what's nice about today you know [smiling voice]".* Anne, 69 years

Other participants, such as Ken and Margaret, also acknowledged unhappiness and ongoing challenges but re-framed them by comparing them to those of others perceived to be less fortunate. For Ken, this approach was guided by his spiritual beliefs:

> *"I mean my suffering is nothing so [...] although I feel a bit down, I look at what's happening around the world, or even what's happening around the corner, and think,' well gee it's not that bad'".* Ken, 66 years

For all participants positive reframing was a conscious and practised strategy to help accommodate autism in later life in a way that was emotionally palatable. Even Margaret, who found the autistic diagnostic label particularly confronting, was able to put a positive spin on it:

> *"You know you're so much better off than most of the planet. Yeah but I mean it [autism] can't be any worse than living in a war zone, can it? You know what I mean? Seriously. I mean I've thought about all these things".* Margaret, 69 years

8.4 Sub-Theme 4. Contentment

***"I'm quite happy doing what I'm doing, actually"* – Margaret, 69 years**

Older age had culminated for most participants in a sense of contentment in later life, a time when they could savour the aspects of life that were important to them and represented the rewards of old age. This was strongly associated with family for some like John who was deeply attached to his wife:

> *"I always say getting old and grumpy together. Ah ... which actually is a wonderful thing to be able to do actually ... is to get old and grumpy together".* John, 74 years

Similarly, Anne expressed an appreciation for reaching later life and being *"lucky to see some grandchildren".* For Ken, implicit in his later-life contentment was the opportunity to savour time with his wife but also, like Anne, time with his grandchildren was a source of pleasure:

> *"You know and I enjoy life ... you know through both our efforts we've got a reasonably comfortable life ... um ... ah ... but um we've got the time and the opportunity to do a lot of stuff, you know, and particularly our grandchildren".* Ken, 66 years

For some, such as Paul, contentment was experienced as having reached a stage in life where he no longer felt pressure to conform to society's standards. There was a sense that being selective about pursuing what was important to him contributed to his contentment with life:

> *"So ... by other people's standards I probably lead an ... awful narrow closed life ... full of routine but, of course, it's what suits me and in doing that of course I'm avoiding all the potential problems".* Paul, 53 years

Similarly, Jane had placed limits on her life that she felt had made "*most of my life a lot better*". By contrast, once again, Charles' experience was more complicated, perhaps as a reflection of the far less fulfilled and supported life he had experienced up until this point. He also expressed a degree of contentment in later life because with retirement "*thank GOD – I don't have anything to do with anybody I don't want to*", [for the] *"first time in my life I can actually do what I want to do [laughs, deep full laugh]*". But he also revealed a starkly different and contrary view with his regret that it was "*highly unlikely that in this world, and in this lifetime, I will achieve anything that is personally satisfying to me*".

Overall, however, there was a sense that participants, including Charles in his moments of optimism, shared Anne's view that:

> *"I think I've become … oh I don't know … probably in the last sort of five years I've become quite sort of* ***happy in my age*** *if […] you know what I mean? And I'm happy".* Anne, 69 years

8.5 Sub-Theme 5. Family

"The family is obviously extremely important to me" **– John, 69 years**

Family featured in the life stories of all participants but there was diversity in the experience and importance of family. As noted above, contentment for a number of participants was also bound up in the concept of "family", and Chapter 6 described how family featured as support for, and a source of, social interaction. Thus, family was a positive and significant presence in diverse ways at various stages of life for almost all participants, and stories of family were interwoven throughout all interviews. But it's inclusion as a sub-theme in this chapter is representative of its far more explicit and positively pervasive role as a symbol of what was good about life *now* for most participants. Ken summed this up when he described with such intense love his relationship with his grandchildren:

> *"I* ***love*** *our interactions with them [grandchildren] which we usually do together. I really love those kids you know…".* Ken, 66 years

In some cases, an "adopted" family – close friends made through work or hobbies – was preferred, rather than the biological family. Rose described a strong preference for her "chosen" family which was driven by a desire for freedom from family conflict and the ability to choose to live life as she wished rather than as dictated by her mother and sibling:

> *"I'm looking forward to celebrating Christmas here in [place] this year. With the family I choose. Not the family I'm born into".* Rose, 66 years

Family Christmas was a touchstone for Jane too. She had reached a stage in life where she was highly selective of her social interactions, which were determined by her emotional capacity and tolerance levels. For her this involved a narrowing of her family focus, moving away from her extended family in favour of more time with her immediate family:

> *"I boycotted Christmas last year. [...] It was just the two of us for Christmas and there was a big shindig at Mum's and I was still recovering from the year before. I just said – I told her in August – I just said I'm not coming at Christmas. I just can't do it anymore [tears well up again]".* Jane, 55 years

But, again, only Charles was the divergent case with his description of outright rejection of his family. Charles' complete disconnection from his family was in stark contrast to the other participants and was at the extreme end of the continuum in terms of family relationships. Even Doug and Anthony, who had also had less contact with their immediate family (e.g., siblings) since early adulthood, had not detached themselves completely and expressed joy in their respective grandchildren and children.

8.6 Sub-Theme 6. Humour

***"It's funny, but it's sad"* – Anne, 69 years**

Without exception the participants in this study shared their life reflections with humour. The humour was self-deprecating, wry, and typically directed at themselves. In some instances, it seemed humour was used as a tool to deflect from, or "make fun" of, behaviours or experiences that may be perceived by others as unusual. At other times there was a poignancy to it; a sense that it was used as a coping mechanism to camouflage, or re-frame reflections and memories tinged with sadness or sorrow. It frequently took the form of genuine and robust laughing, but there were also examples of smaller laughs, gentle smiles and twinkling eyes which punctuated the interviews. Although most interviews also bore witness to tears in the telling of stories of lifelong hurts and sorrows, the seriousness of these accounts was invariably lightened with a laugh or a smile. The effect was that all interviews were infused with a poignant but nonetheless positive energy. Perhaps this was a deliberate and well-practised strategy, as Rose's comment suggests:

> *"And I've also learned tools to handle things better. That's why ... this situation [muffled]. That's why I could ... OK ... let's put a little humour in it instead of starting cursing [laughs]".* Rose, 57 years

What is clear from this final sub-theme is that in later life autistic adults can see life with unexpectedly uplifting humour. This is something that is not often apparent in the literature and suggests, as Anthony observes, that "*Aspies need a better marketing department*".

8.7 Discussion

The final theme in the analyses of interview data, *Poignancy and Positivity*, encapsulates participants' generally positive outlook on life – as Anne described it, a sense of being "*happy in my age*". This was an unexpected and novel finding. This theme was supported by six sub-themes: independence and autonomy; awareness and acceptance; positive reframing; contentment; family; and humour. While some of these sub-themes were consistent with those identified in other recent qualitative studies that have investigated ageing in autism (e.g., Hickey et al., 2018; Hwang et al., 2017; Lilley et al., 2022), that they contributed to an overarching pattern of positivity suggests parallels with phenomena such as the positivity effect (Reed et al., 2014) and the paradox of ageing (Charles & Carstensen, 2010) characteristic of successful ageing in typically developing adults.

The sub-theme of independence and autonomy encompassed aspects of later life from which participants derived pleasure, such as freedom and achievement, but it was also discussed as important emotionally and at a practical level in terms of personal control. The importance of embracing and maintaining independence in later life has been highlighted as a key consideration for research on ageing and autism (Edelson et al., 2019) and was a concern voiced by the middle-aged participants in this project who feared aged care systems might not meet their autism-specific needs. This concern ties in with the sub-theme of treatment wariness, discussed in Chapter 7 on emotion regulation, and further highlights the importance of addressing distrust for health professionals and the perception that autistic adults are not listened to or understood in health settings. This is particularly important because functional independence is critical to psychological wellbeing and successful ageing (Baltes & Carstensen, 2003; World Health Organization, 2020), but so too is interdependence (Ng et al., 2020) which in later life can require accepting assistance from others. Balancing and supporting later-life autonomy and independence with interdependence, even in aged care, is possible but targeted interventions and training that are person-centred and take into consideration person-environment fit and intrinsic capacity are key to this (Baltes & Carstensen, 2003; Springstein et al., 2022; World Health Organization, 2020). Legitimising fears voiced by the participants in this study, loss of independence may result in undermining autistic individuals' self-efficacy and control over their own lives; assumed incompetence can be exhausting for people with autism because they over-compensate to prove their abilities or to achieve desired goals (Webster & Garvis, 2017). Given healthcare professionals report limited experience or training in autism in general, much less in older adults (Unigwe et al., 2017; Zerbo, et al., 2015), ensuring that there is an understanding of the importance of not overprotecting older autistic adults, or inadvertently encouraging dependency, aligns with calls for a strength-based approach to ageing in autism (Hwang et al., 2017) and will be vital to ensure older autistic adults are able to maintain their desire for independence and the benefits to healthy ageing that ensue.

The sub-theme of self-awareness and acceptance reflected the outcome of participants' reflections on life with the benefit of time, experience, and knowledge. However, contrary to other research findings (Hickey et al., 2018; Lilley et al., 2022), while participants' autism diagnosis was a factor in this process, it was not necessarily the catalyst or fundamental to their self-identity in later life. Typically developing older adults also perceive self-awareness as an important aspect of successful ageing (Reichstadt et al., 2010). Life review and realistic self-appraisal allows older adults to accept the past and focus on making the most of the present, a process that middle-aged autistic adults have also engaged in (Webster & Garvis, 2017; 2020) irrespective of the timing of their diagnosis. Thus, while it might sometimes coincide with diagnosis, the emergence of greater self-awareness in older autistic adults such as those in the current study might also be evidence of a normative late life psychological process involving life review more generally (Reichstadt et al., 2010). Further, in line with qualitative studies of middle-aged autistic adults (e.g., Webster & Garvis, 2017), participants in this study revealed that self-awareness led to an acceptance of personal limits, including those attributed to aspects of autism. This gave participants new-found confidence to identify and pursue personal goals and activities that were meaningful to them, a process that is also characteristic of successful ageing (Baltes & Baltes, 1990; Baltes & Carstensen, 2003).

The relatively positive outlook of participants in this study reflected a consistent tendency, when reflecting on the past, to focus on the positive aspects or outcomes of sometimes negative experiences. Again, while this was in distinct contrast to the older adults in Hickey et al. (2018) whose experiences of loneliness and social isolation were characterised as defining "growing old and getting older with autism", a tendency to positively re-frame memories and attention, the supposed "positivity effect" (Reed et al., 2014), aligns with qualitative reports of successful ageing in typically developing older adults (Reichstadt, et al., 2010). Positive reframing of life's events and experiences by participants in this project did not preclude moments of regret or sadness, and a co-occurrence of positive and negative emotions throughout the interviews, most clearly demonstrated by the juxtaposition of tears and humour, was a clear sub-theme in the present study. This suggests the possibility that, as has been found in studies on emotional experiences in later life in the general population (Carstensen et al., 2011) and building on the findings described in Chapter 7, autistic older adults may experience poignancy and greater emotional stability in older adulthood. The two are interrelated with wellbeing (Carstensen et al., 2011) and further exploration of these aspects of emotional experience might go some way to explaining conflicting findings across different domains of subjective quality of life in autistic people (Howlin & Magiati, 2017; Mason et al., 2019), and provide context and clarity to findings that older autistic adults report higher levels of subjective wellbeing and social, psychological and overall QoL than younger autistic adults do (Roestorf et al., 2022; Yarar et al., 2022).

Closely related to the sub-theme of positive reframing was the novel finding that participants in this study, particularly those in the young old age band, were relatively content in their old age, and happy to focus on life in the present rather than go over the past or worry about the future. To our knowledge, neither quality has been identified or explored as a potential factor in autistic outcome at any stage of life although both have been mentioned in previous qualitative research. Although Lilley and colleagues (2022) also observed contentment in older autistic adults, it was described as deriving from feeling self-contained. By contrast, in the present work, contentment was framed in terms of savouring the rewards of post-retirement and other aspects of later life from which participants derived a sense of satisfaction. This is consistent with older typically developing adults who report more contentment than younger adults in life satisfaction studies, and is thought to be an example of positive adaptation in later life that contributes to enhanced wellbeing and successful ageing (Bowling, 2007). While it's possible the preference of most participants in the current study to focus on the pleasures of their lives "now" might represent a shift in perspective attributable to relatively recent diagnosis (Hickey et al., 2017), typically developing older adults also exhibit a present-focused perspective, and this is consistent with SST. Thus, an alternative interpretation could be that with perceived constraints on time left to live these participants are motivated to prioritise a focus on the present rather than the future (Carstensen et al., 1999; Carstensen et al., 2011; Charles & Carstensen, 2010).

Family, and "adopted" family were reported as being important to all participants in the later stage of their lives, in terms of support but also for the pleasure derived from the close emotional relationships and social interactions they afforded. It is known that families are a major source of support for autistic individuals (Lord et al., 2020) and this finding goes some way to addressing the gap in our understanding of how family influences social and psychological outcomes in autism in later life (Howlin & Magiati, 2017; Mason et al., 2019). Moreover, the range and level of family interactions reported in this study give context to its potential importance as a key modifiable factor in positive outcomes in autism. However, it is also worth noting that participants' preference for selectively pruning social networks and prioritising meaningful relationships that are less likely to be unpredictable or entail conflict is an emotion regulation strategy used in later in life to enhance emotional experience (English & Carstensen, 2014; Sims et al., 2015). In this context, rather than evidence of autism-related social isolation, the prioritisation of family over other relationships by participants in this study could be evidence of adaptive developmental changes in social and emotional life in older autistic adults similar to those seen in the general population (Carstensen et al., 2003; Charles & Carstensen, 2010; Fredrickson & Carstensen, 1990). Thus, it may be likely that the familiarity, predictability, and overall positivity of family relationships was sufficient to meet participants' social and emotional needs and therefore contributed to their wellbeing (Carstensen et al, 1999). Rose's case provides further support for this interpretation. She reported selectively distancing herself from her biological family, with whom she experienced ongoing conflict, and instead prioritised her "chosen" family with whom she felt more comfortable, accepted, and emotionally supported. It could be argued that surrounding herself with an emotionally satisfying and meaningful social network in this way is an example of adaptive emotion regulation by selective pruning (Carstensen et al., 2011; English & Carstensen, 2014). Charles, as a counter-case in the family sub-theme, lends more weight to this proposition. With his rejection of family, coupled with few other consistent social connections in other facets of his life, it seems likely his social network was too small, leaving him socially isolated, more susceptible to mental health problems, and therefore more vulnerable to an overall poorer outcome in later life than the other participants (Charles, 2010; Charles & Carstensen, 2009).

Overall, the theme of poignancy and positivity, supported by the sub-themes of independence and autonomy, awareness and acceptance, positive reframing, contentment, family, and humour, suggest that participants in this study enjoy a generally positive outcome and outlook in later life. The positivity reflected by the label of this chapter's theme and the nuanced insights revealed in its underlying sub-themes, were unexpected given the prevalence of negative stereotypes about ageing generally, and particularly ageing in autism, that seem to predominantly inform research priorities amongst researchers and autistic individuals. This highlights that there may be a genuine risk that researchers' expectations inadvertently cloud, or at least restrict to a negative focus, research decisions and data interpretation about autism and ageing. Whether the positivity identified in the current sample is by pure sampling chance or is evidence of a pattern of social and emotional ageing in older autistic adults that parallels that of typically developing peers needs to be tested empirically. For instance, research has found that people with impaired executive control, an area of difficulty for many autistic people (Wallace et al., 2016), may not exhibit the same effect (Sims et al., 2015). Similarly, mental health issues, loneliness, social isolation, and negative life events – all associated with autism – may compromise or negate the known age-related advantages of ageing (Charles, 2010; Charles Carstensen, 2010) as Charles' divergent case suggests. Nonetheless, the findings presented here suggest that positive outcomes are at least possible for some autistic adults in later life (Scheeren et al., 2022) and provide invaluable insights and context based on personal autistic experience. That is an encouraging start.

8.8 Summary of Thematic Findings and Conclusion

In summary, analyses of participant experiences formed four overarching themes: negotiating diagnosis and an autistic identity in later life; social instinct; mental health problems and solutions; and positive outlook. Within these themes and their underlying sub-themes were nuanced similarities and differences according to participants' stage of life. Indeed, many of the characteristics and patterns in social and emotional functioning identified in Chapters 5 to 8 have received little attention in autism studies but are consistent with lifespan developmental models of successful ageing.

Firstly, Chapter 5 outlined how participants' pathways to and subsequent responses and acceptance of diagnosis and autistic identity followed a distinct pattern according to age and stage of life. Young old participants' diagnoses frequently were the result of external factors and triggered ambivalence; being autistic was acknowledged but as just one part of their identity. By contrast, middle-aged participants' diagnoses were the culmination of a quest for self-knowledge and autistic identity was generally embraced.

In Chapter 6 the theme of social instinct and its underlying sub-themes revealed that despite continuing to experience difficulties with social interaction across the lifespan, participants mobilised personal strengths, self-determination and social self-efficacy to selectively compensate for perceived weaknesses in social abilities. Participants were motivated to adapt to the social world in pursuit of social and emotional connections that were personally meaningful. There was a preference for smaller social networks comprised of emotionally close family and friends.

The theme of emotional downs and ups in Chapter 7 encapsulated the changing patterns in participants' experiences and management of emotional regulation difficulties over the course of the lifespan. Subthemes revealed a downward pattern in the frequency and intensity of participants' reported experiences of mental health problems. Employment and relationship issues and life transitions were common triggers throughout adulthood. However, despite emotional downs such as ongoing treatment wariness and regrets and self-blame, there were also personal gains such as greater self-regulation and resilience.

Finally, in Chapter 8 sub-themes of independence and autonomy, awareness and acceptance, positive reframing, contentment, family and humour contextualised participants' relatively positive outlook later in life in the overarching theme of poignancy and positivity.

In conclusion, to our knowledge this study is one of, if not the first, to provide context to the possibility that like their neurotypical peers older autistic adults can have a positive outlook on life

(Howlin & Magiati, 2017; Mason et al., 2019; Scheeren et al., 2022) and, subjectively at least, a good outcome consistent with successful social and emotional ageing. Whether the social and emotional trajectory of ageing in autism can be understood from a broader lifespan perspective has not been considered but it seems that it should be. The next section of this thesis will explore the psychological theory of lifespan development and the proposition that lifespan developmental psychology might be a useful framework for understanding and promoting healthy and successful ageing in autism.

PART III: THE FUTURE

Chapter 9: Proposing a Lifespan Developmental Psychology Approach to Autism and Successful Ageing

***"I'm being more 'me' as I get older"* – Jane, 55 years**

Negative social stereotypes of ageing in today's world emphasise decline rather than the potential for growth in later life. Misconceptions about old age as a time in life limited by impairment, loss of autonomy, loneliness, depression, and an overall poor quality of life is a common negative perception (Staudinger, 2015). This is even the case amongst health professionals who are informed by traditional medical models in which ageing is couched in terms of burden and disease (Bowling & Dieppe, 2005). Many of these negative stereotypes are also associated with autism (Howlin, 2021). It's hardly surprising then that international autism researchers have identified an urgent need to investigate the "double-whammy" of being autistic and ageing, with both autism-specific and age-related challenges to navigate (Sonido et al., 2020), and how best to ensure quality of life and well-being for older autistic adults (Edelson et al., 2021; Graham Holmes et al., 2020; Howlin, 2021; Roestorf et al., 2019) being of critical concern.

But ageing is more complex than just biological or cognitive decline and loss; it is also a period of psychosocial development, striving and contentment (Baltes & Carstensen, 2003; Pruchno, 2021; Eendebak & World Health Organization, 2015). Paradoxically, despite declines in physical health and cognitive functioning, in the general population older age is associated with higher self-rated successful ageing (Jeste et al., 2013). Indeed, the majority of typically developing older adults are quite satisfied with life and may experience a peak in emotional wellbeing well into their 60s and 70s (Carstensen et al., 2011). Global public health responses are shifting towards greater understanding and promotion of successful ageing (Jeste et al., 2013) with the focus as much on promoting healthy ageing through recovery, adaptation, and growth in later life as it is on addressing losses (Eendebak & World Health Organization, 2015). Preventative and medical care are important aspects of maintaining health and longevity in later life, but they are not enough to ensure quality of life – successful ageing is also important and depends on psychological factors (Bowling & Iliffe, 2011) including resilience, optimism, and wellbeing (Jeste et al., 2013). These concepts are consistent with the shift in the World Health Organization's conceptualisation of healthy ageing away from a disease focus and towards a functioning-based approach. According to

WHO, healthy ageing is “the process of developing and maintaining the functional ability that enables wellbeing in older age” (World Health Organization, 2020). Intrinsic capacity, all the “physical and mental capacities” that an individual can draw on, combined with environmental factors (e.g., emotional and relational supports, systems-level services and attitudes), determines their functional ability “to be and to do what they have reason to value” (World Health Organization, 2020, p. 12). It is comprised of interrelated domains including psychological and cognitive capacity which play a role in older adults’ ability to learn, grow and make decisions in ways that enhance social and emotional growth and provide a sense of control in the pursuit of personally meaningful goals. That is, to age successfully.

Contemporary gerontological theory and research has focused on the concept of successful ageing (Pruchno, 2021; Riffin & Löckenhoff, 2015) as a natural progression of lifespan[2] development and adaptation (Baltes & Baltes, 1990; Wahl et al., 2017). From a lifespan developmental perspective, successful ageing is multidimensional and broad enough to encompass losses in physical, psychological, and social functioning, disease and disability (Bowling & Iliffe, 2006; Tesch-Römer & Wahl, 2017) as well as gains derived from adaptive coping strategies and life experiences (Baltes & Baltes, 1990; Baltes & Carstensen, 2003). Personal meaning and goals, the culmination of an individual’s unique development, experiences, and social conditions, are the index for successful ageing (Bowling & Dieppe, 2005) and “success” may or may not align with ideal or statistical norms, (Baltes & Carstensen, 2003). This conceptualisation, and recognition of the potential value of subjective measures in assessing successful ageing across cultures and population subgroups (Jeste et al., 2013), is consistent with calls from autistic adults, advocates, and researchers for a strengths-based approach to exploring autistic outcomes that evaluates autistic people’s life goals, personal experience and needs rather than objective outcomes prescribed and measured by others (Pellicano et al., 2022). It is also flexible enough to give consideration to the wide variety in autistic individuals’ social, cultural and environmental life contexts (Howlin, 2021; Hwang et al., 2020; Lord et al., 2022; Pellicano et al., 2022; Shattuck, 2020; Woodman et al., 2016).

There is not yet a unifying framework in autism research within which to understand autism in adulthood (Shattuck et al., 2020), let alone successful ageing, although many have been proposed. Orthodox biomedical frameworks have been criticised for their focus on functional

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[2] As this chapter is about *lifespan* developmental psychology it uses ‘lifespan’, the term preferred by developmental psychologists (Baltes, 1987), rather than ‘life course’, which predominates in sociology (Mayer, 2003) and has been adopted by some autism researchers who discuss ageing and autism from a socioecological perspective (e.g., Shattuck et al., 2020; Wright, 2016).

deficits and failure to capture – or enhance – flourishing in autistic lives (Pellicano et al., 2022). While Rowe and Kahn’s biomedical model of successful ageing has been recommended by some autistic researchers and advocates for its focus on active engagement and relationships (Perkins, 2016), as discussed in Chapter 3 it has also been criticised for failing to flexibly encompass self-reported autistic strengths associated with successful ageing (Hwang et al., 2020). Similar concerns have been raised about the biomedical approach to understanding and supporting successful ageing in the general population because it underestimates the value of older adults’ psychological resources in effectively coping with the inevitable challenges of old age (Bowling, 2007; Bowling & Iliffe, 2011). Autism (and ageing with autism) has also been analysed from a diverse range of sociological, philosophical, cultural and activist theoretical frameworks and discourses including: social identity theory (Cooper et al., 2017; Cooper et al., 2021; Perry et al., 2021); a positive disability identity framework (Smith & Jones, 2020); critical theory (“critical autism studies”; Woods et al., 2018) and cultural ideology; socio-ecology (Edelson, et al., 2021; Wright, 2016; Wright et al., 2019); self-determination theory (Webster & Garvis, 2020); dialectical misattunement hypothesis (Davis & Crompton, 2021); Nussbaum’s capabilities approach (Pellicano et al., 2022); the social model of disability (den Houting, 2019); and Damien Milton’s (2012; 2014) sociological and social psychological perspective which also draws heavily on the social model of disability. Many of these frameworks focus on deficits and disability even as they advocate for a positive neurodiverse conceptualisation of autistic adulthood. There are also concerns that there is too much focus on impairments associated with individual characteristics, with interventions and treatments designed to “change the individual”, rather than targeting the broader social and environmental contexts that prevent autistic people from reaching their full potential (Pellicano et al., 2022). Further, none adequately address the likely heterogeneity of autism in older adulthood and, as autistic people themselves are concerned to know, whether “autistic individuals may have different developmental and prognostic trajectories associated with variable patterns of strength and abilities as well as challenges and vulnerabilities, any and all of which may evolve differentially over the life course” (Edelson et al., 2021, p. 384). Case studies of late-diagnosed autistic adults confirm the unique vulnerabilities of older autistic adults when faced with critical life turning points such as loss of a life partner or retirement (James et al., 2006; Mukaetova-Ladinska et al., 2012; van Niekerk et al., 2011), but they also highlight that despite significant interpersonal and social difficulties many of these people were able to negotiate life’s challenges relatively successfully up until these life crises. While still more prevalent than in typically developing adults, mental health difficulties in older autistic adults seem to abate in older autistic adults (Lever & Guerts, 2016b), a finding that has been described as “jarring” and perhaps a result of the “healthy survivor effect” (Tse et al., 2021). Yet from a gerontological perspective a decline in mental health issues in later life is not unexpected; there is the same pattern of lower levels of depression and anxiety in older than younger people in the general population (Hoertel et al., 2013; Blazer & Hybels, 2005; Remes et al., 2016). It is essential that the vulnerabilities and susceptibilities of autism to poor outcomes are investigated and understood. But could there be a flipside? Could it be that the paradox of ageing extends to autism as well? Isn't it equally important for autism research to consider the potential for flourishing in later life?

There is potential for adaptive change in autism (Frith, 2004) – the notion is after all inherent in its label as a neuro*developmental* condition – but this has not been as widely recognised or acknowledged as it should be (Lord et al., 2022). This contrasts with research on the developmental trajectories of other neurodevelopmental conditions such as ADHD and schizophrenia. Although these conditions are extremely heterogeneous there are similarities too; ADHD is one of the most commonly co-occurring conditions with autism (Rosen et al., 2021) and the two are strongly genetically correlated (Lee et al., 2019; Thapar & Rutter, 2021). Identifying parallels with other conditions can benefit autism research (Rutter, 2005) so it is worth considering that older adults with ADHD report better quality of life in the psychological health domain than do younger adults with ADHD, are better able to engage in effective emotion regulation strategies (Thorell et al., 2019), and report a decline in the impact of ADHD symptoms in later life (Michielsen et al., 2018). Similarly, individuals with schizophrenia experience improvements with age in psychosocial functioning, wellbeing and mental health (Jeste et al., 2011; Van Patten et al., 2020). Although there is variability in the personal trajectories of schizophrenic people, for many there is improvement in social integration in later life, and the perception of successful adaptation to their condition through positive coping strategies including selective engagement in supportive social networks (Cohen et al., 2020; Jeste et al., 2011). It seems logical then to further explore the possibilities suggested by similarities in these patterns to recent findings in autism research. For instance, a higher self-rated social quality of life in older than younger autistic adults (Yarar et al., 2022), and a strong correlation between subjective wellbeing and objective psychosocial functioning in autistic adults, both of which improved with age (Scheeren et al., 2022). Could it be that, in common with these other conditions and with "typical" development, in autism there is a relatively similar psychological trajectory across the lifespan culminating in improved subjective wellbeing in later life? Perhaps consideration of ageing on the autism spectrum in the context of diagnostic characteristics alone is too simplistic an approach and risks overlooking other, potentially more influential, features associated with successful ageing (Crimmins, 2020; World Health Organization, 2020).

A developmental lifespan perspective has already been identified as vital in autism research (Thapar, Cooper & Rutter, 2017) because it helps identify key transition points from childhood through to adulthood that might contribute to meaningful outcomes for autistic adults (Lai & Szatmari, 2019). But applying such a perspective, within a systematic framework, to understanding how older autistic adults have navigated life's journey – the types of interpersonal relationships, environments and opportunities that have helped them do so with relative success – might also illuminate our understanding of ageing in autism and the factors that contribute to positive outcomes or otherwise in later life.

Lifespan developmental psychology[3] is one such perspective represented by a broad meta-theoretical framework formulated over many years by Paul Baltes and colleagues (Baltes, 1987, 1997; Baltes and Baltes, 1990; Baltes et al., 2006) to conceptualise successful ageing in the context of adaptive change over the lifespan. That is, "ontogenetic development as the dynamic interplay of gains and losses", an adaptive process with the goal being the relative maximisation of the former and minimisation of the latter (Baltes, 1997). As such it is also concerned with adaptive processes and strategies informed throughout life by factors such as resilience, well-being and experiences of emotional distress that promote successful ageing (Charles & Carstensen, 2010) while also accommodating individual and environmental variation (Baltes & Baltes, 1990). The concept of adaptation is not new to autism and stretches as far back as Kanner's follow-up account of the "social adaptation" in adulthood of many of his original patients (Kanner, 1972), and Asperger's observation that "adaptation to the social environment" was evident in the majority of his cases who had developed "compensatory abilities to counter-balance their deficiencies" (Asperger in Frith, 1991). These early perspectives foreshadowed the relatively recent shift in autism research to framing autism as a form of human variation (Lai et al., 2020), albeit for some with attendant impairment and disability (Baron-Cohen, 2017; den Houting, 2019). This shift has given rise to an orientation away from narrow normative assessments of autistic outcomes and quality of life in later life (Edelson et al., 2020; Roestorf et al., 2019; Pellicano et al., 2022) in favour of a balance of subjective and objective benchmarks that more fully capture the heterogeneity of autism (Lord et al., 2020).

Understanding and developing approaches to successful ageing from a psychological perspective offers flexibility to accommodate aspects of ageing across a range of abilities and care needs (Tesch-Römer & Wahl, 2017) such as those represented by the autism spectrum and is far

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[3] 'Lifespan developmental psychology' is often shortened to 'lifespan psychology' (Baltes et al., 2006). The two terms are used interchangeably in this chapter.

more predictive of improving and maintaining quality of life than biomedical or health approaches (Bowling & Iliffe, 2006). For these reasons, framing the experiences of older autistic adults in the context of lifespan developmental psychology has several advantages. It can offer novel evidence-based theoretical interpretations of emerging research on autism over the lifespan and in later life; highlight research opportunities to broaden our understanding of ageing on the autism spectrum; and help identify novel clinical and intervention opportunities to enhance the potential for positive outcomes – successful ageing – for autistic individuals across the lifespan and into old age. Contemporary lifespan developmental models are informed by Baltes and colleagues' lifespan perspective and the fundamental importance of interindividual variability and intraindividual plasticity to successful ageing. From these key concepts the general model of selective optimisation with compensation (SOC) was proposed to explain how individuals adapt to developmental losses. Subsequent models have built on SOC and gone beyond its "domain-general" focus on the adaptive process of managing a shift in the balance between gains and losses in ageing to focus on specific domains of psychological development and associated mechanisms that promote lifelong adaptive functioning. Of particular relevance to the current body of research, the developmental trajectories of social and emotional functioning in autism, are the domains of motivation and emotion. Thematic patterns in previous chapters have discussed the SST model that was developed to explain adaptive processes relating to these domains in the context of the developmental trajectory of social and emotional functioning in autism. Therefore, the remainder of this chapter will take a broader, more general lifespan perspective on successful ageing through the overarching model of SOC from which SST was derived. Firstly, this chapter will give a brief overview of the theoretical propositions underpinning lifespan developmental psychology. Secondly, the psychological model of selective optimisation with compensation (SOC) derived from this framework will be briefly described, with reference to relevant literature on autism and ageing. Finally, three case studies from the current research program will be presented and examined from the perspective of lifespan developmental psychology and SOC, with particular focus on how these approaches might (re)shape our understanding of, and contribute to future research on, autism and ageing, particularly successful ageing.

9.1 Psychological Theory of Lifespan Development

Lifespan psychology is particularly relevant to autism and ageing because it is interested in both development within the individual and variation in interindividual developmental trajectories across the entire life span. More broadly, it aims to:

> Offer an organised account of the overall structure and sequence of development across the lifespan; identify the interconnections between earlier and later developmental events and processes; delineate

> the biological, psychological, social, and environmental factors and mechanisms which are the foundation of lifespan development; and finally specify the biological and environmental opportunities and constraints that shape lifespan development of individuals including their range of plasticity (modifiability). (Baltes et al., 2006, p. 570)

According to this framework, mastery of changing developmental opportunities and constraints – that is, building and enhancing resources and capabilities – in early and middle life is critical to maximising gains and minimising losses throughout adulthood and, ultimately, successful ageing (Baltes & Carstensen, 2003; Ebner et al., 2006). It is supported by seven theoretical propositions that set out an overarching view of the nature of development and culminate in the proposal of a psychological model that proposes a systematic approach to understanding human development: the effective coordination of selection, optimisation, and compensation (Baltes, 1987; Baltes et al., 2006)[4]. These propositions are summarised in Table 7. Relevant (but not exhaustive) examples and evidence in autism are also noted to highlight parallels with each proposition.

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[4] For a more detailed exploration of the historical, philosophical and theoretical background of lifespan developmental psychology, which is beyond the scope of this chapter, see Baltes (1987, 1997) and Baltes, Lindenberger and Staudinger (1999, 2006).

Table 7

Lifespan Developmental Psychology Theoretical Propositions

Proposition	Definition	Selected evidence/examples in autism
1. *Lifelong development*	Human development continues across the entire lifespan. Developmental change is co-constructed by biology and culture and may originate in birth or at a later point of time in life. Patterns of change can be diverse according to timing, direction, and order. Biological development, social expectations or personal actions can trigger developmental tasks. Developmental tasks may be age-relevant or driven by historical or non-normative influences.	As autism is a neurodevelopmental condition, there is an expectation of development over the lifespan (Lord et al., 2022). Although Kanner and Asperger were both clear that a longitudinal approach to autism was necessary to understand its developmental trajectory over the lifespan, gradually research narrowed in on autism in childhood, with little attention paid to later life (Mukaetova-Ladinska et al., 2012). The opposite phenomenon, a disproportionate emphasis on adulthood, was levied at lifespan researchers (Baltes, 1987). Now, lifespan developmental psychology acknowledges the value in the "reciprocal connection" between childhood and adulthood in promoting a lifespan perspective of human development. Autism researchers are beginning to do the same.
2. *Multidirectional and multidimensional*	In individual development there is diversity in the direction of change in "categories of behaviours", with the possibility for both increases and decreases in functioning in the same developmental period. Similarly, across any number of domains of functioning there is an interplay between external and internal factors that also influence development. Multidimensional models of successful ageing that encompass a range of perspectives and interventions across physical, social functioning and psychological domains have been found to be the best predictors of quality of life (Bowling & Iliffe, 2006).	For comprehensive reviews on multidirectional and multidimensional influences in autism see Happé and Frith (2020) and Lord et al., (2022).

Proposition	Definition	Selected evidence/examples in autism
3. *Dynamic gains and losses*	Development is a constant process of jointly occurring growth and decline across the lifespan. One cannot happen without the other. Selective adaptation engenders gains in adaptive capacity and also losses for alternative pathways and adaptive challenges.	This general concept is touched on in Lord et al., (2022) and later in this chapter.
4. *Plasticity*	There is intra-individuality in the potential for individual development depending on the influence of uniquely personal life experiences and conditions. Importantly, lifespan psychology is concerned not just with the potential (reserve capacity) of individual plasticity but also with the limits (constraints) of development and performance.	The potential for change in autism is explored at length by Lord and colleagues (2022).
5. *Paradigm of ontogenetic, historical and biocultural contextualism*	Drawing on socio-ecological perspectives, lifespan psychology posits that environmental as well as social and biocultural contexts have a role to play in creating opportunities or limiting an individual's developmental pathway (Baltes & Smith, 2004; Springstein et al., 2022). Interactions between normative age-graded, normative history-graded and non-normative (i.e., idiosyncratic) biocultural components contextualise individual developmental outcomes according to how they are processed, reacted to, and acted upon. All three of these influences include biological and cultural or environmental determinants but in different ways. Normative age-graded influences are related to chronological age and are relatively predictable (e.g., physical maturation or socialisation of age-graded life events). Normative history-graded influences are associated with historical time, either in terms of long-term changes over time or one-off events (e.g., war,	In ageing and autism research there is increasing acknowledgement of the need to account for the influences of age, temporal and cohort effects on lifespan development (Wright et al., 2019). Of particular relevance to ageing in autism are normative history-graded and non-normative factors and influences. Changes in the naming and diagnostic criteria of autism from DSM-III through to DSM-5 is an example of a normative history-graded influence that has had significant impact on the way autism is understood, identified and supported. There have also been history-graded changes in sociocultural attitudes to autism which have seen a paradigm shift in the way autism is understood; no longer as a disability but as a form of neurodiversity (Baron-Cohen, 2017), a term that in itself reflects the notion of interindividual difference so integral to lifespan psychology. There is also an emergence of autism activism within a social justice paradigm that seeks to reframe

Proposition	Definition	Selected evidence/examples in autism
	pandemic). Non-normative influences are not associated with a predictable individual or historical developmental dimension but rather occur or follow an idiosyncratic pattern. History-graded and non-normative influences become more dominant with age. Historical and socio-cultural conditions and their evolution over time influence age-related individual development. Biocultural and social changes, and associated cohort effects, may also play a role in ontogenesis.	the way autism is understood and positioned in society, and challenges traditional approaches to scientific research (Ne’eman & Pellicano, 2022; Pellicano & den Houting, 2022; Pukki et al., 2022). Research agendas are changing accordingly as they are increasingly informed by autism stakeholders rather than only scientific researchers and clinicians. There is a strong focus on participatory research designs that includes autistic people and other key stakeholders. A lifespan developmental example of a history-graded influence is Kanner’s (1972) conclusions from the longitudinal follow-up of his original childhood autistic cases. He noted their developmental changes in self-concept and social adaptation (which in the autism literature today is more commonly referred to as camouflaging) did “not run counter to the general run of the population (p. 32)”. That is, at that period of social history and psychological thought, adaptation was seen as a normative human process, and its evidence in autistic adults was interpreted by Kanner as an example of how autistic people were similar to rather than different from the average person in their social behaviour. Current conceptualisations of compensation in autism are more complex and autism-specific. Non-normative events can have long-term and life-changing implications for social roles, status and self-identity and have the potential to overtax reserves and create disruption and uncertainty depending on their timing and other life events (Baltes & Smith, 2004). Such an example in autism is late-life diagnosis which can precipitate a critical life turning point with implications such as a change in self-identity from “different” to one that incorporates a diagnostic label.

Proposition	Definition	Selected evidence/examples in autism
6. *Multidisciplinary*	Lifespan developmental psychology is open to the integration of interdisciplinary perspectives and contexts, such as the integration of a bioecological perspective outlined above. Without such, behavioural developmental theory would be incomplete.	Acknowledgement of the value of a multidisciplinary perspective is growing in autism research. For instance, bio- and socio-ecological frameworks are increasingly recommended and used in relation to addressing gaps in systems-level supports for autistic people across the lifespan (e.g., Howlin, 2021; Lai et al., 2020; Shattuck et al., 2020; Wright et al., 2019)
7. *Selection, optimisation, and compensation*	The psychological model **selection, optimisation, and compensation** offers a systematic view of successful development – and ageing – as, subjectively and objectively, a process of maximising gains and minimising losses through a dynamic interaction of selection, optimisation and compensation that increases in response to the pressures of ageing. The processes of selection and selective adaptation are inherent to development and driven by biological, psychological, cultural and environmental factors. Optimisation brings about advances in development and is gradually overtaken in later life by compensation as more resources are channelled towards managing loss.	The notion of maximising gains and minimising losses is not new to autism. What is maximising potential and minimising barriers (Lai et al., 2020) if not a version of the same goal in the context of autism-specific strengths and difficulties? Supporting people with autism across a range of needs and contexts is already informed by this proposition. Clinical care, childhood treatment programs, adolescent social skill and vocational support groups and adult employment support programs developed and tailored to maximise autistic strengths while minimising the difficulties is also consistent with this idea. Similarly, Asperger cited the workplace as an avenue for social integration and in some cases significant career success in his more intellectually capable cases. He attributed this to "compensatory abilities to counter-balance their deficiencies" (Asperger, 1991; p. 88). The way in which he linked the adaptation of these cases' special abilities to "outstanding achievements" in their chosen (selected) careers foreshadowed the concept of selective optimisation with compensation postulated by Baltes and Baltes (1990) as a suitable model for understanding development in autism.

9.2 Selective Optimisation with Compensation and its Relevance to Autism and Ageing

The general model of selective optimisation with compensation (SOC) was proposed to explain how individuals adapt to developmental losses as they age. In contrast to Rowe and Kahn's biomedical model, this foundational lifespan model draws on evolution and human ontogeny as a basis for its premise that individual development is a lifelong process of adaptation and balancing gains with losses at all ages and stages of life through the orchestration of inherent subprocesses of selection, optimisation, and compensation (Baltes, 1987). In older age, "success" is an adaptive balancing act managed through the selection of age-appropriate goals and by shifting the focus of goals in later life from growth to maintenance and the prevention of losses (Ebner et al., 2006). Inevitably there are more losses (e.g., biological, cognitive) than gains, although later-life gains, such as wisdom and dignity, are still expected. Pursuing and achieving a delicate balance between the two becomes increasingly difficult with age, but remains a motivation, albeit one informed by an expectation of changing ratios, as the balance tips away from success to failure.

SOC posits that there are three main functions (and ultimately outcomes) of development that determine the investment of resources, and these are mostly aligned to stage of life. In childhood there is adaptive growth, a focus on allocating resources towards higher levels of functioning and adaptive capability; in adulthood the focus shifts towards maintenance and resilience despite life challenges or losses; and in later life resources are primarily invested in regulation and management of loss, although resilience is maintained. Baltes and colleagues propose that the three key strategies inherent to these functions and outcomes, selection, optimisation and compensation, describe a "*general* process of adaptation" (Baltes & Baltes, 1990, p. 21) in which heterogeneity and plasticity are both implicit and explicit. According to this model, developmental outcomes are not specified or "required" for successful ageing, and extensive variation in goals and the developmental pathways by which they are attained is expected. In this sense SOC is universal (i.e., any developmental process is understood to encapsulate selection, optimisation and compensation) and relative (i.e., there will be variations in resources and the criteria used to define successful ageing). This flexibility suggests that SOC is a model that could be useful for framing our understanding of the lifespan trajectory of autism and particularly the likely heterogeneity of ageing in autism.

Successful ageing in the context of SOC is framed by seven key propositions (Baltes & Baltes, 1990). These, and parallels in autism research and findings, will be outlined briefly to set the context for a deeper exploration of SOC and how it might provide a comprehensive model for understanding and framing existing and future research on autism across the lifespan, but particularly in ageing.

First, there are major differences between normal, optimal, and sick (pathological) ageing. It is the latter that is thought to have the potential for resulting in a qualitatively different experience of old age rather than “ageing” itself. This proposition is highly relevant to autism. Although it is a neurodevelopmental not a pathological condition, it is nonetheless characterised diagnostically according to qualitative differences in social interaction and communication. Autism and the associated notion of neurodiversity (Baron-Cohen, 2017) are umbrella terms for a spectrum of abilities and functioning, ranging from medical “disability”, when symptoms result in clinically impaired functioning and intervention is required, to “difference”, characterised by atypical behaviours that, depending on context, may not necessarily impact on functioning (Lai et al., 2020). It remains to be determined if and how these qualitative differences in autism might evolve with development and plasticity over a lifetime; whether they too might result in different experiences of ageing for autistic individuals with different levels of functioning; and how best to tailor interventions and supports to ensure successful ageing across the board.

Second, there is much heterogeneity (variability) in ageing. This relates to cognitive, behavioural, and social outcomes all of which are subject to individually different processes and effects. Again, what is well known about autism is that it too is a highly heterogenous condition. The sources of variability likely in ageing are equally evident in autism, with outcomes influenced by such differences as the genetic and biological underpinnings of autism, individual effects such as adaptive functioning, intellectual ability and personality and, as mentioned above, different patterns in co-occurring health conditions, such as mental health problems, across the lifespan (Lord et al., 2020; Robinson et al., 2020). Contextual and cultural influences also contribute to heterogeneity in autistic outcomes (de Leeuw et al., 2020). There is also substantial heterogeneity in the developmental trajectories of autistic adults (Happé & Frith, 2020; Howlin, 2021; Lord et al., 2020), with some experiencing lifelong social and daily living difficulties while others develop and finesse skills that allow them to get by in everyday life (Lai & Szatmari, 2019). This heterogeneity on multiple levels has made it difficult to identify a unitary psychological explanation for autistic features (Happé & Frith, 2020) further supporting the premise that in autism too ageing is unlikely to be a uniform process.

Third, there is much latent reserve. This premise is based on the notion of plasticity. Ageing research has found that there is considerable intraindividual plasticity in older adults and this can be activated through new learning and training which in turn enhances adaptive capacity and can lead to late-life growth. While there is still much to be learned about the conditions necessary to facilitate behavioural plasticity in later life (Staudinger, 2020) behavioural optimisation and compensation are possible, and there is the potential for maintaining levels of functioning in various life domains including social functioning. However, in everyday life older adults' adaptive capacity can be at risk of being underestimated or not activated if the environment, or structural context, reinforces social scripts of dependency (Baltes & Baltes, 1990; Springstein et al., 2022) or lacks stimulation (Van Patten et al., 2020).

As a neurodevelopmental condition it follows that in autism too there is the potential for change across the lifespan (Lord et al., 2022). The notion of plasticity in autism has been most heavily focused on the critical period of early years brain development (Lord et al., 2020). For instance, interventions designed to improve young children's adaptive behaviour and targeted supports and programs throughout the school years are aimed at developing and enhancing independence, daily living skills, social interaction and emotional regulation (Lai et al., 2020). The potential for behavioural plasticity in adulthood has been explored through psychosocial interventions to enhance social functioning (Bishop-Fitzpatrick, Mazefsky, et al., 2017), but there remains a lack of empirically evaluated interventions for this stage of the lifespan (Pallathra et al., 2019).

Socio-ecological factors such as stereotypes and environmental barriers can also stymy opportunities for autistic adaptation in adulthood (Lai et al., 2020). An obvious example of latent reserve in autism is the high levels of underemployment or unemployment in autistic adults (Robison, 2019; Woolard et al., 2021) that continues into later life (Sonido et al., 2020) despite a high proportion having average IQ and post-secondary school qualifications (Happé et al., 2016; Lounds Taylor et al., 2015). Stereotypes about autistic abilities and underestimation or assumed incompetence can be exhausting for individuals who over-compensate trying to prove their abilities (Webster & Garvis, 2017). A focus on physical and social workplace environments and employment support programs can harness and develop autistic individuals' abilities and strengths and lead to improved employment outcomes for autistic adults (Lai et al., 2020; Lorenc et al., 2018) as well as promote self-belief in their ability to achieve desired goals (Webster & Garvis, 2017). However, greater awareness of the potential for change in autism across the lifespan is crucial to ensure the development of enhanced-education, community, and clinic-based programs to promote long-term positive change and outcomes (Lord et al., 2022). In autism, as in ageing, it has been proposed that taking a multidisciplinary approach to supporting autistic adults across the lifespan through policy, educational, employment and advocacy and stakeholder involvement is crucial to minimise barriers and to create opportunities that optimise person-environment fit and maximise potential (Lai et al., 2020). In other words, to harness latent reserves by creating autism-friendly environments that support adaptive growth.

Fourth, there is an ageing loss near the limits of reserve. This relates to the limits of behavioural capacity and adaptivity. While evidence suggests there are age-related limits in typically developing older adults compared to the young, in autism evidence is emerging that this may not always be the case. For instance, in some domains there may not be the same patterns of age-related functional decline in autism as there are in typically developing adults (Happé & Charlton, 2012). Differences in cognitive functioning between typically developing and autistic older adults appear to become either less obvious or equivalent. In the case of theory of mind performance, age may even be a protective factor with differences no longer observable let alone in decline (Lever & Geurts, 2016a; Yarar et al., 2020). Nor does there seem to be an age-related loss in autism in other components of social cognition, such as self-reported empathy (Yarar et al., 2020). These different socio-cognitive patterns in autism might (tentatively) support speculation and anecdotal evidence that some aspects of behavioural capacity and adaptivity in social situations do not approach the limits of reserve with ageing in autism in the same way as is proposed for typically developing adults (Happé & Charlton, 2012), but empirical evidence is needed.

Fifth, knowledge-based pragmatics and technology can offset age-related decline in cognitive mechanics. The premise here is that despite losses with ageing there is capacity – latent reserve – to compensate for or offset those losses. Thus, it is thought that factual and procedural knowledge can be harnessed and applied where cognitive mechanics are less reliable than they used to be. As discussed above, although there is compensation in autism for difficulties associated with autistic characteristics, there might not be the same decline and consequent need for an increase in offsets in some aspects of cognitive functioning, such as theory of mind, as there is in typically developing adults. Evidence from clinical observations and qualitative studies suggests that many autistic people develop and hone the use of intellectual strategies throughout life to compensate for difficulties associated with autistic impairments in social interaction and communication (as opposed to losses due to ageing). As Temple Grandin explained, “social adaptation has to proceed via intellect” (Grandin, 2006, p. 153); rules are learned, and situations are decoded and analysed using logic and intellect to develop strategies and techniques for managing social interactions (Webster & Garvis, 2020). Similarly, the proposition that technology is used to make up for decline or deficits in areas of functioning is of relevance to autism, not just in later life but across the lifespan and, most obviously, in the domain of social functioning where technology (e.g., a preference for communicating electronically, or socialising via online chatrooms and community websites) can circumvent difficulties (rather than losses). Autistic adults report relying on online or technology-based communication as an alternative and less stressful means of communication (Müller at al., 2008) to assist with employment opportunities (Lai et al., 2020), mental health support (Gaigg et al., 2020), reducing loneliness (Umagami et al., 2022) and establishing relationships (Müller et al., 2008).

Sixth, with ageing the balance between gains and losses becomes less positive. This proposition follows from the lifespan perspective that development at any stage of life is characterised by the dynamic interplay between gains and losses, with the expectation that in later life, both subjectively and objectively, there will be greater losses than gains. Baltes and Baltes (1990) posit that this is inevitable because developmental change across the lifespan involves specialised adaptation; positive changes in adaptive capacity necessarily come at the cost of alternative developmental options. In ageing this is especially the case as the limits of reserve capacity are gradually and inevitably exceeded by life tasks. This shift occurs at a subjective level too, where losses are anticipated although some gains, such as greater self-acceptance and contentment (Reichstadt et al., 2010), are too. One way of interpreting late diagnosis in older autistic adults who present with mental health or other difficulties after a lifetime of relative success and productivity might be that it is the result of this shift in the interplay between losses and gains. Loss of family support (e.g., due to death of a supportive spouse or parent) represents a sudden removal of an important resource for navigating life, exposing a shortfall in reserves when life's demands, possibly exacerbated by grief, become overwhelming and unmanageable. There is also autistic burnout (Miller et al., 2021; Raymaker et al., 2020), whereby an accumulation of life stressors and expectations build to a point that becomes overwhelming and outweighs the autistic individual's ability to manage them, resulting in detrimental impacts on mental health, day-to-day functioning, and quality of life. In line with the shift described by Baltes and Baltes, autistic adults have reported reaching the limits of their functioning capacity and having to manage "reduced tolerance to stimulus" (Raymaker et al., 2020 p. 136). This comes at a cost – for example, the need to take time off work, social withdrawal, and prioritising and reducing activities – but, also with benefits such as the attainment of greater self-knowledge (Raymaker et al., 2020; Webster & Garvis, 2020).

Seventh, the self remains resilient in old age. Despite negative stereotypes of ageing, as has been discussed in this and earlier chapters, the paradox of ageing is that older adults enjoy high levels of subjective life satisfaction and self-rated successful ageing, the latter of which has been associated with resilience (Charles & Carstensen, 2010; Jeste et al., 2013; Scheibe & Carstensen, 2010). According to Baltes and Baltes this can be explained by an individual's ability to alter their frame of reference for life goals and expectations according to changes in their living situation, life transitions, age and stage of life and associated reference groups, and by drawing on life experience. As for typically developing adults, it has been proposed that how autistic people interact with their environment can determine their developmental health and resilience (Szatmari et al., 2016). However, it has been suggested that a focus on risk factors in autism has been at the expense of understanding more about protective factors that might lead to better than expected "resilient outcomes" (Szatmari, 2018, p.227). In autism, how resilient outcomes is defined – that is, "doing OK" in a life lived as desired and meaningfully, and irrespective of co-occurring psychiatric or other conditions (Lai & Szatmari, 2019) – provides another example of how thinking in autism research is already embracing that of other disciplines such as occupational therapy and education, and indeed lifespan developmental theory. In line with this view, Lai and Szatmari (2019) suggest that a lifespan perspective is warranted to examine older autistic adults' experiences of life challenges, and how they have dealt with them, to gain insights for developing strengths-based approaches to enhancing well-being in autistic people. This suggested approach represents a shift from a predominantly individual-based to a socio-ecological based perspective that includes the investigation of unexplored family and contextual variables potentially implicated in the development of resilience in some autistic adults (Szatmari, 2018) who might be deemed to have achieved a good outcome or successful ageing.

In summary, according to lifespan psychology successful development is dependent on an individual's "efficacious functioning" in a particular system (e.g., psychological, social), domain (e.g., family, employment, recreation), or task (social integration, self-actualisation, cognitive performance). Developmental goals and outcomes are not prescribed. Rather, attainment is evaluated according to an individual's personal goals, and may vary depending on whether attainment is assessed by objective or subjective criteria, judging authority (e.g., ranging from the individual to family or culture), or norms (e.g., functional, statistical, ideal). Building on reserve capacities in these areas of functioning in early and middle life paves the way for successfully mastering developmental tasks later in life. Pulling this together, then, in the SOC model the definition of success is goal attainment, and successful ageing is "minimization of losses and maximization of gains" through the dynamic (i.e., constantly evolving) processes of selection, optimisation and compensation (Baltes & Carstensen, 2003, p. 88). The theoretical intent is that these processes represent human development – and ageing – as successful adaptation that may incorporate psychological mechanisms and strategies that vary from one individual to another depending on their desired goals, time, or the context.

As a model of lifespan development, SOC explains how individuals select and pursue achievable developmental goals according to their life situation through maximising available resources and compensating for barriers or losses that impede the realisation of those goals. Empirically, SOC-related behaviours have been found to be useful for understanding life-management strategies and successful ageing (Ebner et al., 2006; Freund & Baltes, 1998, 2002; Wiese et al., 2000, 2002). Strong relationships between each SOC process and subjective indicators of successful ageing, particularly satisfaction with ageing, and reduced social and emotional loneliness, have been found and remain even when controlling for age, subjective mental and physical health, intelligence, and other factors such as control beliefs and personality style. In old age the use of SOC processes can be protective in the face of restricted or declining resources (Freund et al., 2017).

9.3 The Processes of Selection, Optimisation and Compensation

Following is a summary of the component processes of SOC. These are interactive processes that work in combination to achieve desired goals and outcomes (Freund & Baltes, 2002). Parallels with autism research will be discussed in the following section.

9.3.1 Selection

Selection, regarded as the “cardinal principle” of adaptive ageing (Baltes & Carstensen, 2003), is about narrowing personal goals and life domains to which resources are channelled according to the context of converging environmental demands, personal motivations and skills, and biological capacity. There are two types of selection distinguished by causal and functional antecedent conditions: elective selection is motivational selection whereby there are a number of optional pathways to choose from, and one is selected as the priority. Elective selection may relate to new domains, tasks or goals but is always a readjustment that involves trade-offs between alternative pathways. Alternatively, where there is a loss of functioning, or a lack or expectation of changed means in individual or environmental resources, there is loss-based selection. This type of selection requires an adjustment or reconstruction in aspirations or goal priorities (Baltes et al., 2006). Selection can be proactive or reactive, and changes may be environmental, behavioural or passive, but invariably involve self-efficacy to deal with losses or difficulties perceived as challenges in ways that satisfy personal goals. Goal selection can also be influenced by social expectations about age and stage of life (Freund et al., 2017). Selectivity has been found to increase in middle and later-adulthood. Unlike young and middle adulthood, when potential pathways are explored, in older adulthood resources are increasingly channelled into more specific personal priorities (Freund & Baltes, 2002). Socioemotional selectivity, discussed in previous chapters, is an example of how later-life selection in the social domain drives a deliberate restructuring or refining of social networks to prioritise time spent with close emotional partners rather than others. This strategy is thought to be adaptive because it promotes emotional satisfaction in later life.

9.3.2 Optimisation

This is a process of selective adaptation and reflects the concept of plasticity that is so integral to lifespan psychology and SOC. It involves striving for greater efficacy and enhanced functioning in a goal domain of personal importance or expertise. Optimisation comes about through the enrichment and augmentation of internal or external reserves and resources and relies on socio-cultural knowledge, goal commitment, practice and effort. Critically, optimisation is also dependent on the availability of opportunities; it requires appropriately stimulating and enhancing environmental contexts and may be stifled in restrictive or overprotective contexts.

9.3.3 Compensation

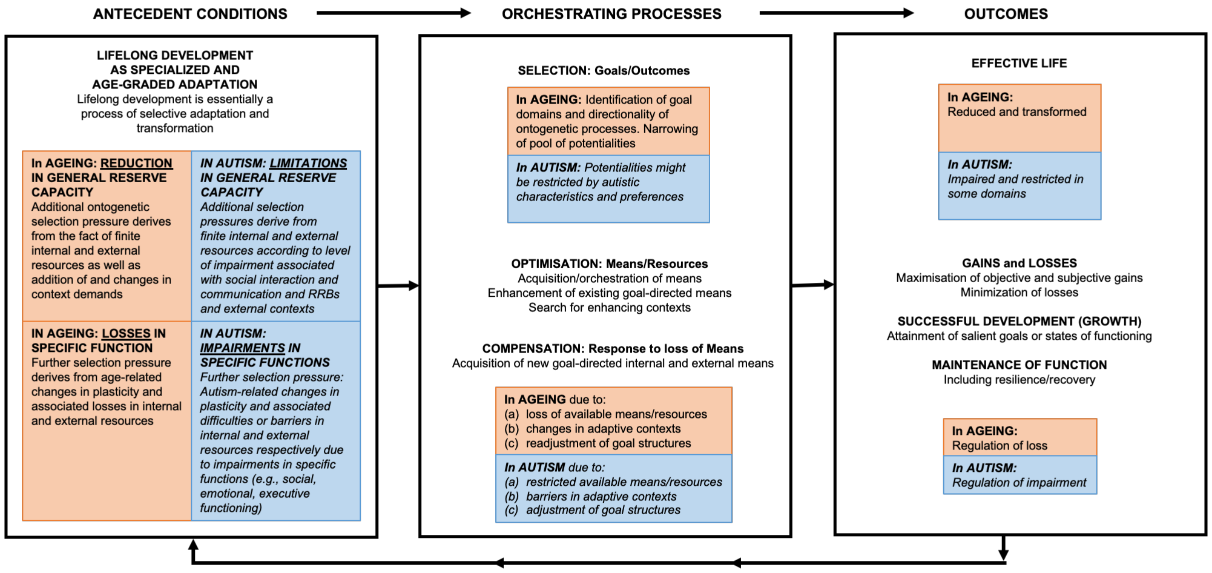
Baltes' (1997) seminal paper on SOC notes that compensation, one aspect of autistic functioning currently at the forefront of research, is especially, and perhaps counterintuitively, relevant to human development because in stressful or challenging conditions "innovative efforts", borne of deficits or loss, ultimately result in enhanced adaptive capacity. Thus, according to SOC theory, compensation takes place when adaptive potential or range of plasticity is restricted. That is, when behavioural capacity is lost or falls below what is necessary for effective functioning, goal attainment and maintenance is necessary through alternate means. Compensation has multiple origins and takes a variety of forms; it may be automatic or planned, psychological, technological, or human (i.e., compensatory assistance in the form of a support person). Lifespan psychology also proposes "culture as compensation" (Baltes, 1987) in the sense that supports across a number of cultural domains, ranging from material, technical, and economic to social and psychological, are critical to offsetting biological declines and maintaining functioning in later life. Selection and optimisation can necessitate compensation, and according to the underlying theory this is evidence of the dynamic between gains and losses in development, and the interactive nature of the three coordinated processes (Freund & Baltes, 2002). Compensation can involve the allocation of resources towards one goal (selection) but at the expense of another ("negative transfer" (Baltes et al., 2006, p. 593). Compensation may also become optimisation depending on context and developmental "space" with some compensation-based behaviours evolving over time and with practice.

9.4 SOC – Evidence From Autism

Are selection, optimisation, and compensation, as conceptualised in the SOC model, evident in autistic behaviour over the lifespan? It seems likely, especially if we consider that Baltes and Baltes propose that selective optimisation with compensation is a flexible lifelong phenomenon with universal application to human development. This universality becomes clear if we substitute the SOC model's antecedent conditions relating to ageing for DSM-5 impairments and deficits in autism (see Figure 5). ASD diagnostic impairments, social interaction and communication and restrictive and repetitive patterns of behaviour, might easily be interpreted at the clinical level as examples of reductions in capacity in Baltes and Baltes' antecedent conditions for SOC processes. Similarly, a valid interpretation of variations in the model's "losses in specific functions" might include the range of autistic difficulties in social, emotional, executive, and occupational functioning domains. Thus, it is proposed that SOC provides a parsimonious process-oriented approach to understanding how autistic older adults – and indeed autistic individuals at any stage of development – can select, compensate, and optimise to maximise the attainment of personal goals across the lifespan and enjoy successful ageing.

Figure 5

The Processes of Selective Optimisation with Compensation Adapted as a Conceptual Framework for Autism Across the Lifespan and in Old Age



Note. Adapted from Baltes and Baltes (1990) and Baltes et al. (1999).

9.4.1 Selection in Autism

It has already been proposed in previous chapters that older autistic adults use selection as a social strategy and to enhance emotional wellbeing. The literature reveals countless other examples of both elective and loss-based selective behaviours in autism, ranging from choosing types of social interactions, leisure activities and work environments in a range of formats and structures based on personal socio-cognitive motivations and abilities, interests, talents, and sensory sensitivities and according to socio-cultural context. Rather than being unique to autism, it can be argued that these examples of using selection to determine how best to channel personal resources is evidence of autistic individuals engaging in adaptive behaviour typical of human development. However, the universality of this adaptive process is not often explicitly recognised in autism research which is increasingly focused on socio-ecological solutions to ensuring quality of life for autistic individuals. For instance, in some cases autistic individuals' "self-selection" behaviour is overlooked or re-badged as a response to environment-driven phenomena such as "niche construction" and "environmental accommodation" (Livingston & Happé, 2017) that are more likely to suit the unique needs of autistic people rather than as an example of self-efficacious choice or self-determination. This is not to suggest that enhancing person-environment fit for autistic individuals should not be a key priority, but rather provides support for the contention that selection might be a complementary adaptive process, already in the autistic repertoire, to be considered as a useful behavioural strategy that can enhance quality of life and successful ageing in autistic adults.

9.4.2 Optimisation in Autism

As for selection, in recent autism research the concept of optimisation has centred more on socio-ecological contexts than the internal reserves of the individual. As noted above, there is a growing focus on the importance of environmental accommodation (Howlin, 2021). Strong emphasis is placed on the importance of stakeholders' and multidisciplinary care providers' promotion of autism-friendly changes at a systems-level to create opportunities and optimise person-environment fit (Lai et al., 2020) and, ultimately, better outcomes for autistic individuals across the lifespan (Henninger & Lounds Taylor, 2013; Wright et al., 2019). The importance of person-environment fit is not disputed; it aligns with lifespan psychology's theoretical proposition that socio-ecological perspectives (e.g., having access to facilitative environments) and biocultural context play a critical role in optimising or constraining an individual's developmental pathway. But a stronger emphasis on optimisation in the psychological domain in autism could be of equal value and is in line with changes to the DSM-5 and ICD-11 diagnostic requirements to profile individual strengths that can be used to inform treatment and service needs (Lord et al., 2022). In reality, many autistic individuals already optimise their strengths just as typically developing people do. Repetitive and restrictive behaviours and interests in autism are typically conceptualised as maladaptive but they are also evidence of exceptional strengths integral to optimisation, including patience, persistence, and a drive to practice (Happé & Frith, 2009; Lord et al., 2022) in areas of unique and individual skills, talents, and special interests. This ability to optimise existing strengths and interests has been identified as a valuable adaptive approach for personal development and social integration (Kanner et al., 1972; Heaton 2009) leading to the achievement of personal goals and enhanced outcomes. The notion of harnessing autistic special interests and talents in the classroom and the workplace, and to facilitate opportunities for social engagement more generally, is frequently reported in the literature, but usually as a stand-alone strategy in a suite of other approaches aimed at achieving good outcomes. Treatment success can depend on the unique strengths and interests of an individual (Lord et al., 2022). Investigating ways to incorporate the process of optimisation more deliberatively into autism treatment and support programs, as part of an integrative approach to achieving individualised goals and, eventually, successful ageing, could be of value.

9.4.3 Compensation in Autism

The model of SOC conceptualises compensation as an inherent orchestrating process in *human* development, and in line with this the earliest literature on autism presented compensation as evidence of typical human social adaptation and a positive factor in the relative success of more intellectually able autistic people (Asperger, 1991; Kanner et al., 1972). However in autism academic literature compensation is proposed as "the processes contributing to improved behavioural presentation of a neurodevelopmental disorder, despite persisting core deficit(s) at cognitive and/or neurobiological levels" (Livingston & Happé, 2017, p. 731) and there is debate about whether it is an adaptive coping strategy or maladaptive due to a range of reported negative implications associated with it, which in most cases might be more harmful than helpful (Hull et al., 2021; Livingston & Happé, 2017). There is also speculation that interventions aimed at alleviating core symptoms of autism, and in some instances improving social functioning, may simply burden autistic individuals with an additional layer of compensatory skills to facilitate functioning in a more neurotypical way (Livingston & Happé, 2017). But the current negative connotation of compensation in autism as evidence of a "mismatch between behaviour and cognition" (Livingston & Happé, 2017) rather than as simply adaptive human behaviour (Fombonne, 2020) may be misleading. Clinically, autistic compensation is promoted as an adaptive coping mechanism. In this context, it is considered to be a healthy and generally successful life strategy for autistic individuals that involves self-acceptance of the personal advantages and strengths associated with autism, as well as the challenges, and the pursuit of life goals that accommodate both in a way that is unique and authentic to the individual (Garnett & Attwood, 2022). Furthermore, it is thought that in autism there may be different types of compensation, some of which are superficial and not generalisable across social contexts, and others which rely on cognitive and other strengths. It is proposed that with time and practice the latter form of compensation can become more deeply embedded and flexible and therefore less likely to fail under stress or in novel situations (Livingston & Happé, 2017). This deeper type of compensation is more likely to become second nature (Livingston et al., 2019b; Petrolini et al., 2023). Both these conceptualisations of compensation more closely parallel compensation in SOC; rather than an adaptive response to loss in ageing, it is an adaptive strategy to cope with autistic difficulties and over time has the potential to become a form of optimisation.

Although SOC holds that compensation can evolve into optimisation, contextual variations may influence the desirability or functionality of both these processes (Freund & Baltes, 2002) and context in this respect may also be influential in autism (Cage & Troxell-Whitman, 2019; Petrolini et al., 2023). Both optimisation and compensation may be difficult where individual resources fall below the necessary threshold for functionality or are exhausted and no longer available for other important tasks. For instance, neuroticism, a personality style characterised by anxiety, self-consciousness, and vulnerability, is positively associated with autistic traits (Schwartzman, Wood & Kapp, 2015) and stress and negative affect in autistic adults (van Oosterhout, 2021). It is also negatively related to optimisation as a life management strategy (Freund & Baltes, 2002) suggesting that this component of SOC may be more effortful for many autistic adults. High rates of "autistic burnout" (Raymaker et al., 2020) commonly reported by autistic adults as a consequence of using social compensatory behaviours, can lead to mental exhaustion, exacerbate mental health problems and generally reduce rather than maintain or improve quality of life (Hull et al., 2021; Livingston et al., 2019b) suggesting that compensation may be a less beneficial process for autistic people in some circumstances or according to individual characteristics.

Clearly, compensation in autism is a complex and perhaps somewhat contested concept. Reframing the negative impact of compensation on mental health might be possible by considering it in the context of lifespan development theory and the SOC model. Reported differences in the reasons for and impact of compensating, and changes in willingness or ability to engage in it at different stages of development, are examples in autism of both intraindividual and interindividual heterogeneity, and how the achievement of personal goals requires an ongoing balance between gains and losses (e.g., social interaction and its benefits versus mental health and wellbeing). Thus, it may be that, despite the additional complexities raised in recent research on compensation in autism, it is nonetheless, when understood within a lifespan developmental model such as SOC, evidence of an innate human adaptative mechanism in autism rather than something unique to it.

9.5 Reframing Ageing in Autism From a Lifespan Developmental Perspective

This chapter's proposal of a lifespan developmental perspective to autism and ageing represents a creative and fresh approach to current thinking and future research. It outlines the potential for successful ageing in autism, in stark contrast to prevailing negative stereotypes of old age and the anticipated "double-whammy" of ageing with autism, by proposing a unifying theoretical framework that is based on extensive theoretical and applied work in the field of gerontology and specifically lifespan developmental psychology. This is a novel approach: although the World Health Organisation's conceptualisation of healthy ageing (which includes healthy ageing for people experiencing disability) is based on lifespan developmental psychology, it has never before been considered in the context of autism and ageing.

Further, this chapter provides an innovative alternative perspective on topical and rapidly evolving areas of autism research relevant to ageing, such as compensation, neurodiversity, and the interpretation of objective versus subjective measures of quality of life and outcome for older autistic adults, and in doing so encourages researchers to consider them from an interdisciplinary perspective that challenges expectations and assumptions. Specifically, as outlined in Section 9.4, framing our thinking about autism research and treatment according to each of the sub-components of the model of selective optimisation with compensation suggests new angles for exploring autism and ageing. For instance, investigating ways to develop and assess treatment and support programs that draw on gerontological research on the processes of selection and optimisation (considered to be integral components of adaptive behavioural strategies) and are aligned with developmental stage could assist autistic individuals in identifying, modifying and ultimately achieving individualised goals across the lifespan and, ultimately, successful ageing. Similarly, there might be therapeutic advantages in promoting a reframing of our understanding of autistic compensation and its association with mental health problems by considering it in the context of lifespan development and the SOC model which emphasise the importance of recognising and maintaining a balance between gains (e.g., desired benefits of social interaction) and losses (e.g., stress or emotional burnout) in the pursuit of personal goals.

In closing then, why consider examining autism from a lifespan developmental perspective? What is to be gained from doing so, and how does it contribute to current research endeavours? There are a number of reasons. Firstly, as autism is a lifelong neurodevelopmental condition it seems logical that a lifespan developmental psychology approach and SOC provide an appropriate alternative to the dominant biomedical model of successful ageing. Indeed, both might be useful in understanding autism not just in old age but also across the lifespan. Lifespan developmental psychology is not autism-specific therefore there are no preconceived assumptions about functioning, ability, or stereotypes. It is flexible: it acknowledges and accommodates the heterogeneity of autism, and the notion that everyone is on their own developmental trajectory; it proposes that lifespan development is multidimensional and multidirectional and that there is the potential for change, plasticity, and the possibility for both increases and decreases in functioning in the same developmental period. It characterises development as a constant interplay of gains and losses that require selective adaptation of alternative pathways to meet life challenges. It accounts for the influence of historical, environmental, socio-cultural, and other environmental contexts on life experience and in turn on ontogenesis. And importantly, it echoes the catchcry of neurodiversity by acknowledging diversity as a fundamental aspect of development.

Secondly, and perhaps idealistically, lifespan developmental psychology is optimistic about all human development: it has as its primary goal the examination and promotion of *successful* development, a universal goal for all individuals. Psychology, as an evidence-based discipline, offers innovative perspectives and solutions for tackling psychological, functional, and environmental barriers to wellbeing across the lifespan and successful ageing for a diverse range of people. It is hoped the propositions put forward in this chapter might contribute to and encourage fresh and creative thinking about ageing and autism, and what potential actions, social policies and research initiatives might contribute to promoting successful development across the lifespan culminating in *successful* ageing.

Third, lifespan psychology recognises that development does not take place solely in the childhood years. It continues beyond, and may be informed by, “the aftermath of childhood” (Baltes et al., 2006, p. 644). This is highly relevant to autism research which only recently has begun to extend its focus beyond the early years of development into adulthood and later life. It is clear there is much more work to be done here, and lifespan developmental psychology might offer a useful guiding framework within which to do this.

Fourth, diagnosis alone is not basis enough for efficacious interventions and treatments, and consideration of social context and developmental factors is critical in both research and clinical practice to capture and best accommodate the patterns of development (Thapar et al., 2017). For instance, resilience is a recurring characteristic cited in autism research but its potential importance in development is never given much prominence. It requires further investigation given its strong association with relatively good life outcomes and wellbeing in old age. As is the case for ageing research on other neurodevelopmental conditions such as schizophrenia (Van Patten et al., 2020), a focus on positive psychological characteristics such as resilience but also optimism, wisdom, happiness, and positive self-appraisal in older autistic adults could be useful to our understanding of and ability to promote quality of life and successful ageing in autism.

Finally, there is a need to re-frame negative stereotypes about old age in autism literature. This is important to ensure that expectations about ageing are not focused only on anticipated decline and losses, but also reflect the opportunities for positive life outcomes, productivity, growth, and wellbeing that successful ageing can bring for all people.

Chapter 10: SOC and Successful Ageing in Autism – Three Case Studies

"They say you grieve your losses and then you move on to nice things" **– Anne, 69 years**

So far, we have broadly covered the theoretical background to SOC and lifespan developmental psychology, but can they be usefully applied to real-life autistic examples (in the same way Baltes and Baltes' (1990) described pianist Rubenstein's approach to continuing his playing in the context of selection, optimisation and compensation)? There is a wealth of examples of autistic individuals who have succeeded in life, despite having to contend with often significant difficulties in a world not fully accommodating of autistic traits. The participants in the current research program, who may also be considered as ageing successfully, provide further evidence of this. Thus, this section will analyse John, Anne, and Charles' self-reported life experiences from the perspective of lifespan developmental psychology and the model of SOC. John and Anne were chosen for no other reason than that they were the two oldest participants in this research program. Charles' case offers a clear counterpoint or divergent example of autism and ageing. As with all the participants, John, Anne, and Charles have had challenges throughout life, starting from childhood when they realised they were different from other children, and had difficulty making friends with peers. However, both John and Anne have managed to live full lives and while there are still aspects of their autism that pose difficulties and are cause for regret, both enjoy a level of contentment and satisfaction for a life well-lived that might not have been anticipated in their earlier years. By comparison, Charles has had a less conventional life journey, and his life story represents an "outlier" perspective. While his experiences and viewpoints fall within the patterns of themes identified in previous chapters, they do so frequently as a counter case. Nonetheless, like John and Anne, Charles appears to be happier in later life relative to his earlier years. His contrasting developmental trajectory tests and, it will be argued, validates the flexibility of lifespan psychology and SOC propositions presented in the previous chapter and their applicability to autism. It is hoped that these case study analyses will provide insight into how lifespan developmental psychology and selective optimisation with compensation might contribute to our understanding and support for the achievement of successful ageing in autistic people with a range of experiences and outcomes.

10.1 Case Study 1

"Family is obviously very important to me" – John, 69 years

John lives with his wife of nearly 50 years and self-identifies as having "mild Asperger's[5]". He came to this realisation when he was about 59 years old by which time three of his grandchildren had been diagnosed with autism. John has a Bachelor's degree in chemistry and is fully retired after having worked full-time for most of his working life. He now participates in a voluntary capacity on environmental and political causes that are important to him. John shares the story of his life's journey generously; he answers questions matter-of-factly and with frequent displays a self-deprecating humour. He laughs often.

It is clear that John has given much thought to his life; how it has unfolded, his relationships, desires, challenges and personal goals. John has encountered significant life challenges, including living as a small child through the London blitz, migrating to Australia from England, the deaths of his adult daughter and a brother to whom he was very emotionally close, both of which he described as "traumatic", and a period of depression that forced him to take leave from work and put a severe strain on his marriage. Throughout life, and into the present, the fundamental difficulty of Asperger's for John is "poor socialising ... not always understanding where people are coming from, people don't always understand where I'm coming from". But, when asked what concerns he has about ageing, particularly in terms of his Asperger's, his response is pragmatic but positive:

> *"I'm ... pretty ... confident about the future. You know ... obviously health, health of my spouse and family members. I mean ... that's a major concern. You know, we're getting older and you know health issues come up and that ... but that that ... that's the normal part of life and getting older, you know...I don't think I've got any concerns because of my Asperger's going into the future".*

John's approach to life might offer some insight into his perspective on ageing. The way he has managed his life appears to have been strongly motivated by his love of and commitment to his family, a desire for social connection (in the face of finding it difficult), and a preparedness to engage socially on matters of personal principle. His self-efficacy and determination to pursue these goals is evident in his attitude to life:

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[5] John and the other participants in this case series were formally diagnosed by an experienced clinical psychologist in the course of this research program. For details see Chapter 4.

> *"I take the view if you don't like something I mean you can't complain about it unless you're prepared to do something about it yourself".*

Even before he identified as having Asperger's John was focused on finding ways to circumvent the obstacles created by his social difficulties and environmental barriers, and counterbalanced perceived challenges by consciously harnessing his personal strengths:

> *"I can be very very focused on a single issue. Frequently to the exclusion of other issues which can be [laughs] ... can be an issue sometimes…".*

Throughout his childhood and adolescence John felt that he was always "on the outer" and "never really made genuine friends" but he attended youth groups for social interaction. Later, when they were in their early 20s, John and his wife met at work in England, where they're both from, and "started off being best friends" before moving on to a romantic relationship and marriage. He pursued his goal of forming friendships "of *my own*" ("rather than making friends via my wife or in any other way"), with guidance from his wife – "a fantastic support for me in all of this I have to say" – and by relying on social feedback from family, both compensatory behaviours motivated by his pursuit of making social connection.

In addition to being actively involved with his autistic grandchildren he also worked in a voluntary capacity with a young autistic man, a role he found fulfilling because he felt that his own Asperger's enabled him to better understand and help the individual he was mentoring. In this sense, John was able to turn to advantage – to optimise – his experiences of having Asperger's; it conferred on him a unique ability to understand others who are "special people" like him and to provide advice and guidance. Similarly, his strong interest in environmental issues provided an opportunity to involve himself in local lobbying groups, one of which he was the president:

> *"I make acquaintances through other things like ... you know ... groups I belong to, you know ... I belong to several things – the environment, we do a lot of stuff politically, so I've sort of got a circle of people there you know ...".*

John's work with these young people and his political and environmental volunteering are examples of how he has selectively prioritised his personal goal of making social connections by drawing on the individual (common interests and personal experiences) and environmental (semi-formal, structured community groups) resources he has available to him.

However, along with John's single-mindedness is a tendency to become "over-involved" which at one point in his life culminated in a conflict between personal goals and priorities and contributed to significant mental health, relationship, and workplace challenges. This was a turning point in his life that forced John to make choices for the sake of his and his family's wellbeing:

> *"The stress of the job nearly blew me out [...] This started interfering in my relationship with my wife which probably I even felt was even bigger issue because you know my marriage was so important to me and the fact that my marriage was going through a bad time because of it was really hurtful and I found it really difficult to cope with that".*

As a result of this life crisis John was hospitalised. When he eventually returned to work it was with a different employer and part-time, and a new level of awareness about his personal limits and priorities:

> *"Since I had that major breakdown, I've been very aware of where I'm at emotionally and mentally ... and deal with it before it becomes a major issue".*

For John life now as an older adult is "*mainly not too bad*". There is the overriding sense that John is an engaged citizen and a happy and contented family man who has always, and continues to, deal with life's challenges with determination and perseverance. He believes "self-awareness and knowledge about [Asperger's] is very important for the individual and those around them, "especially their nearest and dearest". Despite past and current regrets, particularly for the lack of what he perceives as personal friends, he has "come to terms with [his social difficulties]" and is accepting of who he is. Over time and with life experience, John has become more selective in making decisions about where and how to channel his resources. As he says with a laugh, "it's all part of the deal". Importantly, according to his own benchmark of success and personal life goals, at which the family is centre, John is content with this life:

> *"I've got a good life with with a with a wonderful wife and a great family so ... I ... all those sorts of normal things are there".*

By his own estimation, then, it appears that John, "getting old and grumpy together [with his wife] …which actually is … is a wonderful thing to be able to do", is ageing successfully on the autism spectrum.

10.2 Case Study 2

***"I've become quite sort of happy in my age"* – Anne 69 years**

Anne was diagnosed with Asperger's syndrome in 2001 at the age of 54. Like John, in many ways Anne's life has been conventionally "*happy*"; she has been married for 45 years, has five children, and seven grandchildren. She established a career as a secondary school teacher of

German and Mathematics, and in retirement is actively involved in a local seniors' group and autism community groups. Anne was warm and engaging throughout her interview; she shared her experiences, insights and feelings eloquently and openly and there was frequent laughter and good-spirited self-deprecation. It was clear Anne had reflected deeply about autism generally and particularly about how she felt it had influenced her life before and after she received her diagnosis. Her responses revealed how she had re-framed her past in the context of her diagnosis, and also how she had integrated it into her life and sense of self since then, with an overarching focus on self-awareness and self-understanding:

> *"I don't look too far into the future now you know ... now ... now's nice ... I can live with myself at the moment, you know— I really can. And it's good".*

It was her children's diagnoses of Asperger's syndrome as young adults that prompted Anne to investigate, just over twelve months later, the possibility that she too had autism. Anne's reaction to her own diagnosis has been complicated. Evident in Anne's choice of language is an element of ambivalence about how fully she has accommodated her diagnosis. Several times she states she is "glad" she has the diagnosis as it has helped her in her quest for self-awareness and self-understanding but, almost every time she says this she lets slip a subtle caveat: "*so* ***in a way*** *I'm glad I found out when I did* [author's emphasis]".

This inconsistency is further borne out by Anne's acknowledgment that she is selective about revealing her diagnosis because she believes it could have negative implications for her socially, and it is clear that it is within the social domain that Anne has spent a lifetime trying to overcome not having "*any social graces*". She has done this by observing others' social behaviour and interactions and copying them as a strategy to negotiate social interactions: "that's gone on, I haven't really changed, that's how I still am you know?".

Nonetheless, it would seem that, by objective measures of both autism and successful ageing, Anne might be an example of a "good outcome". But Anne's life has not been straightforward or easy. As for many late-diagnosed autistic adults, Anne revealed that from a young age she felt different from her peers. But she was also motivated:

> *"I didn't understand myself. I didn't ... right from the start I was always very strange… um I was very determined about things ... my mother told me I was very determined about things I wanted to carry through".*

Anne's home life was unhappy – she had "*a very dysfunctional family growing up*" – and she found forming friendships at school difficult. Social connections were made through team sport:

> *"I felt a sense of belonging when I was playing hockey. I went fairly well in hockey ... [laughs] mainly because I was clever at something, good at something ... That I felt like I belonged you know and I was, I was valued, you know, for what I did rather than for what I was you know?".*

Emotional support was achieved through her love of horses which she claimed "*got me through my teenage years*". Anne was also "*driven to succeed*" and excelled academically at school in subjects she enjoyed, particularly German:

> *"I was so selective in being able to ... um... to learn things ... I think German was um was easy ... was easy for me because I could see the rules and I learnt the grammar and was very organised".*

She capitalised on her academic abilities and began university studies after school but did not complete her bachelor's degree "*for various reasons ... I was very close to finishing my degree, but I never did*", and instead gained a teaching qualification. A teaching post to regional Queensland was an escape for Anne from her unhappy family life and it was here that she met her husband. This was a turning point for Anne – her husband was "*so perfect and so nice and not really macho ... you know just nice*" and "*always ... so supportive*". Marrying her husband gave Anne a new "*special interest*", a personal goal around which she structured her whole life, and invaluable compensatory support. As she explained, she was:

> *"...very strongly motivated to make the marriage work [...] the ... one thing I wanted to do was to be a successful wife and mother, you know, so I made the family number one to the extent that I tried at one stage to finish my degree, but I just could not motivate myself to sit down and to finish the studies".*

But life in a small regional community, where everyone knows everyone's business, can be difficult. Anne still felt like an outsider. So, as she did when she was a schoolgirl, Anne made use of her personal attributes, including being "clever", to create opportunities to develop and practice her social skills, the motivation always being to fulfil her lifelong desire to belong. Having committed to this goal she was dogged in applying her strengths in pursuit of it:

> *"...it's all about learning how you are expected to behave ... and I think that was the thing I ... even when I was married and had two children ... two babies in a big hurry ... you know I had friends – I had parents-in-law up there too who were fairly helpful, but I had friends with young children, and I would sort of ...* ***learn*** *from them, but I wouldn't ... but I didn't ever say "I'm learning from you" or "what would you do in this situation". I watched them*

> *and I would think "oh, OK that's what I've gotta do" but it was all in my head. It wasn't even conscious, you know? [pause] It's funny isn't it? And then when I had the kids small and I was living in [rural region] on a farm I formed a group of what was called then the Nursing Mothers Association which now they call the Australian Breastfeeding Association. I formed that and I started it ... I did a course, a telephone counselling course and all that sort of [thing]. And they ... it was really ... I was really excited to be the leader".*

Anne's description of this time in her life exemplifies her adaptive approach, involving careful selection of social opportunities in which she could maximise (or, optimise) on her intellectual strengths using the (compensatory) supports of family and, in the case of the telephone course, a technological medium that best suited her situation. In later life, because she is "*regarded as a clever person*", she has continued to choose social activities, such as trivia nights and writing the seniors' club newsletter, that *"made me feel, you know, a bit taken care of ... [laughs]"* – that is, included – while avoiding situations she knows will be too challenging. Now Anne has shifted her focus to maintaining a manageable balance between social interaction and time to recharge and rest:

> *"I know in big social situations, you know with [seniors'] club um it's not full on you know, it's sort of chat to this person, chat to that person. So I sort of feel OK after that. But I'm not so keen on small group things. I thought, 'no I can't pretend very well'. [I] need time to reboot and I really ... and I've told [husband] and [husband] knows this ... I really, really need time on my own to be able to keep processing everything really. And not being too hard on myself. It's no good looking back and saying oh I did that badly, that badly ... I'm sort of thinking well you know what's nice about today you know".*

Anne has tackled other pitfalls along the way, including a lack of coping skills to deal with life transitions such as her children leaving home. For Anne, this turning point in her mid-40s triggered a prolonged and ongoing battle with depression and anxiety. During this time Anne started taking anti-depressant medication which she has now "*more or less*" been on for the past 25 years. At one point she fretted that the medication made her "*a bit of a zombie*" and impeded her parenting abilities so she reduced her doses. However, around this time, Anne's fragile mental state was further jeopardised with the emergence of long-repressed memories of the sexual abuse she had endured as a teenager. This was another significant life challenge for Anne:

> *"I couldn't tell any- ... couldn't talk about it... it was the most disgusting, most ... you know terrible, vile thing to have happened ... can't tell anybody, can't tell anybody ...and um then, I thought, 'No I've gotta go back and get some help'. And I hadn't even told [husband]*

> *and then about six – no about four – months later I started going to the psychiatrist again […] and it really did take five years. I couldn't work, you know, I just had to … I went to support groups and I was also well and truly back on the anti-depressants then".*

It seems likely that time and place exacerbated Anne's social difficulties, both before and after her diagnosis, and these environmental factors seem to have had a considerable influence over how she adapted to the world around her and, when the time came, processed her diagnosis. Despite these problems, strong social support seems to have been a critical factor in Anne's outlook on life as *"really good. I'm quite enjoying this time of my life".*

Although Anne characterises her life as being "*a bit of a muddled life, really*" it seems that she has negotiated her life's challenges and difficulties with forbearance and determination. With the support and guidance of a strong and loving life partner and children, and long before she received her diagnosis, Anne successfully adapted strengths associated with her autistic characteristics – intelligence, perseverance and determination, adherence to rules, loyalty, and a sense of fairness – to gradually but consciously develop self-awareness and understanding, characteristics that she credits with helping her to overcome her perceived difficulties and differences and the associated barriers to achieving her life goals. As a result, she is remarkably resilient and "*more aware of myself*", something she deeply values and capitalises on as she continues to pursue self-knowledge and life goals.

Now, in older adulthood, although her life story is one shared with poignancy, and her musings swing from sadness to motivational and inspiring self-talk, there is overall a sense that Anne, in her words, is "*happy in my age*". She is relatively content and positive about life and, it seems, is ageing successfully.

10.3 Case Study 3

"I've known all my life that I'm not like other people. It never bothered me"

Charles, 67 years

Charles volunteered to participate in the current study for purely pragmatic – even opportunistic – reasons. Although he does not specifically self-identify with autism or Asperger's and only considered the possibility that he might be autistic when a friend, "*perhaps the only friend I have at the moment*", suggested to him that he might be autistic, he sees that having a formal explanation for his social difficulties might help him in a new business venture:

> *"I'd never heard the word. Um. And then [friend] mentioned Asperger's Syndrome and I thought OK I've known all my life that I'm not like other people. It never bothered me. Um*

> *and I have my own view as to what that is and why it is. But I've been … I had cancer. Um and being in such dire straits I thought 'Ok, if I can get any sort of medical classification that helps me move forward, I'm in it'. […] So, one of my reasons for getting involved in [this study] was I thought, 'If I go to the government I'm going to have to deal with "straights" and the straightest of straights. They're going to find me weird. It'd be very nice to have a piece of paper that says this guy may be weird but not dangerous, you could say'".*

Despite the underlying optimism motivating Charles' involvement in the current research program, his life has been a difficult one: "*it hasn't been a fun trip*". According to the *Whole of Life Timeline* he supplied at the outset of his interview and elaborated on at length in the two hours that followed, Charles gained excellent academic results at school but found formal education intellectually unstimulating ("*by second year high school I'd decided this is junk, they must teach you the real thing at university. Six months at university and that was it*"); has been unable to remain in the same place of employment for longer than three years ("*I've never had a job that I wanted. Whenever I've gone into a job, I've thought alright I think I can stand this for 12 months*"); and, despite being self-taught in advanced electrical engineering skills (attested to by a sincerely favourable written reference from a former employer; provided[6]), has frequently been either unemployed or employed in unskilled and semi-skilled roles ranging from fruit picking ("*Don't have to deal with people*") to storeman to taxi driver. Charles' timeline notes that he was "*betrayed by family*" – admitted to a mental health hospital – and "*reduced to poverty*" in his mid-30s; endured a series of 21 enumerated personal crises throughout his 40s and 50s including "*poverty*", eviction, homelessness, and a "*suicide attempt*"; was "*completely isolated*" in his mid-50s; and "*socially isolated*" in his late 50s, before experiencing "*poverty*" again aged 59 and bankruptcy at 60. Not long after the last entry in his timeline Charles attempted suicide a second time ("*I'd had enough and that was it*") which precipitated another extended stay in a mental institution after which he was able to receive a disability support pension and permanent accommodation in a public housing unit[7]. Charles' peripatetic life has included periods of time spent working or pursuing backing for his scientific theories throughout Australia, New Zealand, Singapore, China, and the UK, but he has never fully settled in one place for long.

Unlike John and Anne, Charles has no family support, and no other regular support through friendship, work, or other networks. His descriptions of his relationships with his parents suggest a

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[6] At the beginning of his interview, Charles provided an extensive dossier of information about himself. This included his *Whole of Life Timeline*, copies of correspondence, and other material he thought would provide relevant background information about his experiences and world view.

[7] It is likely Charles has other psychiatric comorbidities, but these were not explored in the interview.

deeply fractured family unit. He described feeling a growing sense of alienation from his parents in his early teenage years. As he summed it up:

> *"The whole family situation was something which ... um ... I sort of isolated myself completely from them. Um. Which suited me. Had my own intellectual interests".*

Charles was briefly married in his twenties ("*although it [the marriage] satisfied me emotionally and physically, basically, intellectually we didn't have a lot in common*") after which he resolved to channel his efforts into better understanding himself:

> *"So, after the second sort of real relationship failed, I thought, 'Ok from now on I will stay celibate and solo until I understand ... I can understand myself and I can form a decent relationship'. Thought it might take 10 years, here I am 40 years later. [laughs]. So, no children, no relationships. My brother and sister I haven't seen for 30 or 40 years. My mother I would have seen about 30 years ago, my father about the same. I think he's dead now, my mother probably would be".*

For most of his life, Charles has prioritised his motivation for self-understanding and intellectual stimulation over social relationships and emotional connection. However, despite a dogged insistence that he finds people difficult and wants nothing to do with them – *"most people form dependency in relationships. It's not something I've ever wanted"* – there are many contradictions: Charles oscillates between robustly vowing *"people [...] are a downer"* and professing a desire to find some form of connection with others:

> *"All I know is that for myself I was always interested in a relationship that offered that potential [of shared experience]. Never found it".*

One of the enduring challenges of Charles' life seems to be that there is a desire for social interaction, not necessarily a close emotional bond but a fulfilling intellectual connection, and yet there is also a primitive aversion – perhaps a fear – of revealing emotional vulnerability and the risk of rejection at a very personal level. Certainly, his early close emotional relationships, including what he perceives as his mother's abandonment and the failure of the only two "real" relationships he had in his twenties, left him with a reluctance to expose himself emotionally:

> *"I've realised that my emotional independence in terms of human relationships is like a weapon. People can't hurt me".*

Charles recognises his different approach to emotional attachment and relationships is fundamental to his struggles with social interaction and connection. However, unlike John and

Anne, this does not motivate him to find ways to compensate to achieve more fulfilling social relationships. Even Charles' gravitation towards Eastern cultures, where he felt more comfortable and which he felt were a better "fit" for him, was ultimately stymied by his inability to maximise the personal gains life there might have afforded by accepting the inevitable loss of alternative pathways, specifically the lack of intellectual stimulation he sought:

> *"I've always wanted to find a place – a home for myself – in Asia. I like the oriental people. I feel much closer to them than I ever have to Westerners…"* but *"…their minds haven't developed like the western mind has, and intellectually I find them trivial, which sounds superior but … it's just that um … they're a heart-centred people".*

This disdain for lack of intellectual capability is a consistent theme throughout Charles' interview and suggests an intellectual arrogance and sense of superiority, coupled with a rigidity of thinking, of which he seems only vaguely aware. This undoubtedly must also have caused problems in many of his relationships. Thus, although there is a desire for human connection there is also an (overriding) intolerance of those perceived to be less intelligent or with a different perspective, despite his claims to the contrary, meaning that ultimately Charles' strategy for dealing with social and emotional difficulties has been avoidance:

> *"I don't pretend to understand other people in any depth because they live lives so very different from mine. Ummm and I tried not to interact emotionally with them because … I don't understand them. Umm I don't understand their lives".*

While clearly in some respects Charles lacks insight, he is aware of his "social unconventionality" and its disadvantages in a world ruled by social norms, and sometimes he seeks the advice of his one friend to gauge "how off colour" some of his proposed social preferences and beliefs are. One such example was an email exchange in which Charles sought his friend's opinion on whether he should adopt a "breach of convention" to satisfy his long-held personal preference not to shake hands – as Charles termed it, the "practice of social psychic pollution" – with anyone other than a "close acquaintance". The exchange took place at a time when Charles was seeking to start a new business venture, and his friend advised him to do as he wished, as long as he remained flexible in practising it to avoid thwarting his business goals. It is likely that this unconventionality and inability to adapt flexibly to social norms has contributed to Charles' history of broken employment, variously described in his timeline as the result of "*conflict with management about professional standards*", "*forced resignation*", and "*no work … due to improper actions by [employer]*".

As well as his drive for intellectual stimulation, Charles derives great personal meaning from his pursuit of "spiritual evolution" and this has also shaped his approach to life. This has involved a deep and serious study of psychic and other religious literature since his teens, the practice of meditation, and regular time spent in the Australian bush to take time out from having to "deal with people". Meditation, particularly if it is away from the strictures of city living, often in "doss" houses where privacy is minimal, is clearly an instinctual – indeed likely survival – response to Charles's need for release from the stressors of everyday social interactions and challenges. This is a form of emotional regulation, and also a recharge or re-set that enables him to re-enter society:

> *"You do deep meditation and to do that the only way I've found satisfactory is to go out bush and camp for a week. Um. Your mind settles down to a point where ... it's ah it's a marvellous experience if you can achieve it. You can sit there for a whole day and just watch the sun go past and you feel time moving through you ... and ... you don't come back with ideas as such but you come back with what I can only say must be some sort of energy that then inspires ideas across the next weeks and months".*

Despite his difficulty in recognising and expressing emotions in the context of human relationships, Charles has no difficulty in expressing the positive and moving effect music has on him. Perhaps the one constant in his life, despite solitariness, is his music. From the time he was at school until the present, music, particularly playing music in bands, has provided him with emotional sustenance and been a means for him to find connection with others as well as, at times, support himself financially. With prompting, Charles talked at length about the sensations he experiences when he plays music, and as he did so there was an evident relaxation in the way he held his body, his facial expression, and tone of voice:

> *"The music I have found as the most um ... joyful and um amazing aspect of the society I've lived in. The emotions I've got from music, the playing on stage, um ... ahh ... that has been one of the greatest rewards I've experienced".*

Music for Charles is an escape, provides solace, allows him to express himself and demonstrate intellectual as well as technical mastery, and it provides an avenue for social connection and collaboration – all the things he strives for but seems incapable of achieving through social interaction with others in emotional or professional relationships.

Although he is exceedingly polite and at times his story-telling is infused with humour and a deep and warming belly-laugh, lighting up his face and eyes and hinting at an individual who can enjoy a joke or an amusing story, the overwhelming impression Charles gives is that of a man who has a tendency to verbosity, talks intensely and at length on topics that are highly specialised or conspiracy-related (and in some cases extreme enough to give the impression of paranoia); is disdainful of others and their views if he considers them intellectually inferior; and gives the impression of being less open to the perspective of others if it does not align with his view of the world. At times it required significant effort to draw the interview, even though it was loosely structured to be open and freewheeling, back to some sort of "order". Charles seems to be completely oblivious to his digressions, and their lack of relevance to the context of the interview situation. Similarly, although Charles talks in a formal and eloquent way, he reveals some information, such as about his celibacy and his parents' sexual relationship, that are personal and not usual so early in an interaction with someone in a semi-formal setting, further indicating an atypical style of social interaction. His rigid and uncompromising views; the intensity of the conviction of his beliefs and utter faithfulness to them – while undoubtedly a strength in some ways – are perhaps also one of the greatest underlying causes of his inability to settle into longer-term employment or indeed into any long-lasting close emotional relationships.

Now, in later life, Charles' difficulties in social interaction are ongoing, he remains socially isolated and with a deep sense of alienation from the world around him:

> *"I see this [life on Earth] as a sort of cesspit on the outer reaches of the galaxy, that I've come to learn a few things ... but it's like a a a um a jail term and ah I'm ... at any stage if I were to go home tonight and someone came to me and said, OK you're time's finished ... [slumps on table, enacts relief] ... thank God ... I'd be that glad to be out of here. [...] That is my attitude to life on this planet".*

But again, there are contradictions. By the conclusion of his interview, Charles is once again optimistic. Older adulthood and "retirement", such as it is for Charles, is a stage of life he has embraced:

> *"Now that I'm retired – thank GOD – I don't have anything to do with anybody I don't want to. First time in my life I can actually do what I want to do [laughs, deep full laugh]".*

Charles' case highlights how, by normative standards, autistic people are at risk of being especially vulnerable to poor outcomes in later life. However, it also reveals the complexity of both autism and ageing. Has Charles aged successfully? Based on objective measures of quality of life, Charles' poor mental and physical health, history of un- and under-employment, bankruptcy and poverty, lack of social support, and reliance on social welfare suggest a poorer outcome in later life than might be expected given his intelligence. In terms of subjective measures of wellbeing and successful ageing it is harder to make an assessment. These were not discussed specifically with Charles, so we do not have his considered personal perspective. Nonetheless, against the odds and according to his own benchmarks, perhaps in some ways it could be argued that Charles has aged successfully. Although he shared many times his deep sense of social isolation and emotional distress and hopelessness (e.g., *"I just could not relate to anybody, and I thought I'm better off out of here. I don't want to be here"*), when he was asked to expand on his experience of social isolation, completely unexpectedly (due to assumptions) and contrary to objective interpretations of the word "isolation", Charles replied, *"it was a blessed relief!".*

Charles' interview also revealed evidence of his continuing drive and motivation to pursue his life's interests – his reason for participating in the study was to seek some form of written acknowledgement that his difference was "weird but not dangerous" so he could apply for support to build his fledgling computer business for retirees and unemployed youth; his music and (psychic) spirituality are both ongoing sources of personal and emotional fulfilment; and there is his remarkable resilience, unflinching and uncompromising self-belief, ability to persist despite significant setbacks and, despite everything, his capacity to genuinely and deeply laugh rather than cry. Ultimately, at least in the final moments of his interview, Charles' exhibited an optimism and satisfaction with life:

> *"I am aware that my own life has been unusual. That I've been very lucky in many ways, I've survived, I'm still in robust health ... I've ... some of the things I've been through you wouldn't believe. I'm lucky to be here".*

Perhaps it is the case that in his own way Charles embodies the paradox of ageing.

10.4 Analysis and Conclusions

The three case studies presented here reveal the patterns of similarity and difference – the heterogeneity – in ageing on the autism spectrum, and how these might be understood from a lifespan psychology and SOC perspective. The influence of interindividual and intraindividual differences, social expectations, and personal actions on development across the lifespan is also clearly highlighted. Life experiences and socio-cultural context, particularly the still evolving understanding of and attitudes to autism, clearly contributed to the ways in which John, Anne and Charles responded and adapted to life challenges in pursuit of their personal goals. Both John and Anne's life stories revealed multiple examples of how selective optimisation with compensation played a role in their lives, enabling them to pursue personally meaningful life goals, by compensating in areas of difficulty and building on and enhancing their natural abilities and interests to achieve a level of mastery in important areas of their lives. It could be argued that the outcome for both is that they have aged successfully. Each voluntarily nominated their ability to be "*very, very focused on a single issue*" (John) and "*driven to succeed*", "*so selective*" (Anne) as personal strengths that motivated them to pursue chosen life goals with a singular focus representative of elective selection. Consciously or not, both decided early on what goals were important to them in life and channelled their efforts into achieving them, by maximising their personal strengths and interests. Difficulties were compensated for by relying on the resources available to them (e.g., family support, medication, technology) and using other strategies (e.g., avoidance). For both John and Anne life experience, self-awareness and resilience informed adaptive shifts in motivations and goal prioritisation according to gains and losses.

In contrast to John and Anne's experiences, Charles' life story presents a counter or divergent perspective. This divergence highlights the similarities in John and Anne's experiences and presents an intriguing insight into the heterogeneous nature of autism as well as ageing. In doing so it also tests the applicability of lifespan psychology and SOC to ageing with autism. Are the processes of selective optimisation with compensation as evident in Charles' developmental trajectory as they appear to be for John and Anne? It can be argued that they are, but also perhaps that for Charles they are less obviously adaptive in the context of his vulnerabilities, such as social isolation, which is also so closely associated with autism. For instance, Charles is so uncompromisingly selective about the types of social and emotional relationships and work environments that he is prepared to pursue that for him the risk of social isolation seems to have been compounded. Throughout life Charles consistently selectively avoided social and emotional attachments. It's possible to interpret this selective isolation from others as a form of self-protection or indeed as a form of compensation, but ultimately in his case this strategy seems to have been maladaptive because it left him vulnerable and with limited social support in later life.

Similarly, despite an evidently high level of intelligence, Charles seems to have been unable to optimise. Perhaps this was the single greatest impediment to his ability to successfully realise his personal goals. Although aware of some aspects of his "*extreme personality*", he was unwilling or unable to work around these to maximise the opportunities, when they arose, to harness his intelligence in ways that allowed him to connect with others with similar interests or give him financial independence through sustained employment.

Charles life story presents little evidence of compensation in the way that it is understood in either the ageing or autism literature. This seems to be at least partly due to the fact that although he has always been aware of his difference from others, he has not felt compelled or socially motivated to camouflage or mask it, or to engage in compensatory behaviours that might have enabled him to negotiate his difficulties in ways that enabled him to more successfully achieve life goals. Rather than seek out external supports:

> *"... the very first rule is that you must accept complete responsibility for every single facet of your life. [...] If you accept responsibility for it, then you have control over it. If you say, she hurt me, she's responsible for it, you're handing control to somebody else".*

Although speculative, it's possible that for Charles his strong belief in the powers of the psychic realm as a protection against life struggles and his fierce independence may have been a barrier to, or substitute for, the adoption of a more adaptive compensatory approach. Again, this may have compounded his social isolation and lack of social support.

However, perhaps as evidence of the lifelong nature of human development, and despite the particularly restrictive and limiting autism-related social and emotional difficulties in Charles' earlier life, it can be argued his motivation to "*move forward*" in "*retirement*" through his computer business presents an example of the benefits of selective optimisation with compensation in his later life. Selectivity of personal goals increases in later life, and Charles' strategy to fulfil his need for social interaction and connection at an intellectual level and in a field of personal interest and talent demonstrates this. His motivation to be self-employed in a business involving computers, and potentially appealing to similar-aged adults with at least some level of interest in computing, has the potential to satisfy his desire for intellectual as well as social engagement without compromising his professional integrity or risking the "*boredom*" encountered in previous stints of solitary employment:

> *"I formed the computer club on the understanding that I can deal with it the way I want to. If they don't like me that's fine".*

By choosing to teach computer skills, Charles is optimising his considerable technological skills and mastery in an environment that also allows him to demonstrate his intellectual superiority in a more socially acceptable way. In much the same way as he relied on his friend for guidance on business social conventions, and drawing on difficult life experiences, Charles recognises that for his business to attract clients his "*difference*" and "*social unconventionality*" needs to be counterbalanced in some way that is also socially acceptable. In this context, Charles' motivation to acquire formal documentation of his autism is an example of planned compensation.

In conclusion, this chapter has argued that the case studies of John, Anne and Charles support the contention that a lifespan developmental psychology perspective, particularly as articulated by the SOC model, outlines a general process of human adaptation that might be well-suited to framing our understanding of the developmental trajectory of autism generally, and ageing in autism more specifically. Thus, just as typically developing adults adapt to achieve successful ageing, these cases studies suggest that autistic people can too. Whether they do so, as John and

Anne – and even Charles – appear to have done, by engaging in selective optimisation with compensation presents an enticing avenue for future research.

10.5 Future Research

It is hoped that these chapters will provide a starting point for discussion and future empirical investigation. As a start, a relatively simple and straightforward way to test the relevance of SOC to autism might be to replicate studies already undertaken with typically developing adults[8]. For instance, existing self-report measures could be adapted to investigate whether selective optimisation with compensation could be a useful life management strategy for autistic people, and whether there are age-related motivational shifts in goal orientation and life management over the lifespan (for example, see Ebner et al., 2006; Wiese et al., 2002). Self-report measures could also be used to assess the utility of SOC processes in predicting subjective indicators of successful ageing in autism (e.g., subjective wellbeing, positive emotions and loneliness; for examples, see Freund & Baltes, 1998). Such research might inform novel and unanticipated directions for future autism-specific investigations of life management and successful ageing that in turn could inform social policies and clinical practice.

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[8] There is a considerable body of research on the use of SOC strategies across the lifespan and in various life domains. For an overview see Freund et al. (2017).

Chapter 11: General Discussion

11.1 Summary of Findings

***"Finding a way to live life is important"* – Rose, 57 years**

The purpose of this program of research was to investigate the under-studied area of ageing in autism, particularly changes in the social and emotional functioning of older cognitively able autistic adults across the lifespan and into old age. There were two specific aims. The first was to explore, using semi-structured interviews, the lifetime socio-emotional experiences and perspectives of autistic adults aged over 50 years. The second aim was to investigate the usefulness of lifespan developmental psychology as a framework within which to contextualise and understand successful ageing in autism.

The first part of this research program laid the groundwork with narrative literature reviews of social functioning in autism; the foundations of successful ageing, with a focus on socio-emotional ageing in the general population; and an overview of autism outcomes and factors that might influence developmental gains in autism necessary for successful ageing. The second part of this thesis presented and discussed the results of a qualitative analysis of participants' interview data. Four key themes, each with a range of supporting sub-themes reflecting patterns in participants' experiences, were identified. Firstly, *negotiating diagnosis and an autistic identity* in later life revealed that different pathways to, and acceptance and accommodation of, diagnosis and autistic identity might be influenced by stage of life. A diagnostic label may be less meaningful and even threatening for older adults who have developed a fixed self-identity through a lifetime's worth of experience. Participants' perception that social difficulties do not change over time contextualised patterns in the *social instinct* theme relating to sensitivity, support and the deployment of adaptive social strategies to meet a fundamental need "to belong". *Emotional downs and ups* reflected participants' views that in general past mental health problems had improved, although faith in health professionals had not. Underpinning this finding were sub-themes of greater self-awareness, self-acceptance, and resilience in later life. Finally, the theme of *poignancy and positivity* revealed participants' general orientation to the present rather than the past or the future. This was characterised by contentment and joy in family. The mixture of poignancy and positivity throughout all the interviews was both unexpected and novel and suggested that, as in typical ageing, ageing in autism may benefit from a positivity effect and paradox of ageing.

These findings dovetailed with the third part of the thesis which provided a theoretical framework for the proposition that lifespan developmental psychology might be useful for understanding and promoting strategies for healthy and successful ageing in autism. Themes and sub-themes identified in the qualitative analyses of this thesis suggested parallels between lifespan psychology and recent shifts in autism research. These were explored in Chapter 10 with the presentation of three cases studies analysed in the context of the adaptive processes of selection, optimisation and compensation and revealed that participants reported selecting goals that were personally meaningful and realistically attainable, optimised abilities and strengths to compensate for difficulties, drew on life experience to inform emotion regulation and social strategies in later life, and demonstrated a preference for a positive and present-focused perspective on life. These characteristics are consistent with successful ageing trends in the general population and may be evidence that, despite difficulties inherent to both autism and ageing – paradoxically – autistic older adults experience improved psychological wellbeing in later life.

11.2 Key Points and Research Opportunities

Findings from the qualitative analyses combined with the theoretical propositions and models of lifespan developmental psychology offer some tantalising opportunities for broadening the way we think about and research ageing in autism. Firstly, the different pathways to an autism diagnosis in older adulthood, and responses to and acceptance of it, highlight the heterogeneity in experiences and complexities of late-life diagnosis. One person's "lived" experience may be very different from another's – while some people embrace autism as fundamental to who they are, others see it as just one part of their identity. These results reinforce the importance of considering individual context, including – importantly – stage of life when seeking to meet the needs of older autistic adults throughout the diagnostic process and beyond. Self-identification with or diagnosis of ASCs in later life can have positive and negative consequences as evident in the different experiences of the participants in this study and others (Sonido et al., 2020). In particular, participants' insights offer invaluable clues into the risk characteristics and challenges of older adults seeking a diagnosis and suggest a need for autism-friendly services geared towards responding to different levels of comfort with a diagnostic label. It seems likely that there are additional complexities determined by nuanced but established differences in middle age and old age life stages such as those identified in typically developing adults. Respect for and accommodation of this diversity will be critical in research, and also in treatment and support contexts.

Secondly, a key finding related to the social instinct theme, and one which provided a connection between all the sub-themes, was that despite reporting that social difficulties, and therefore innate social functioning, did not change with age, in many respects participants' social *understanding* and experiences – their social *life* – did change. Here was a modern-day cohort of relatively successfully ageing late-diagnosed autistic older adults who were motivated to pursue social and emotional life goals through various forms of adaptation, the pursuit of which was at times difficult or unsuccessful, but nonetheless brought with it, to varying degrees, self-awareness, self-determination, social self-efficacy and resilience. This evidence of an evolving social instinct supports Kanner's early, and Lord and colleagues' (2022) more recent, proposition that adaptability is possible in autism across the lifespan. Interestingly, although participants in this study reported using compensatory behaviours with mixed results, they nonetheless maintained them in the pursuit of social, relationship and professional goals. This is consistent with working definitions of compensation (Livingston & Happé, 2017) and speculation that for a proportion of autistic adults compensation is vital to achieving life goals (Livingston et al., 2019b) and can therefore be regarded as successful adaptation. This is worth noting because, just as researchers have sought to move the research agenda on successful coping and adaptation in typically developing adults facing adversity from risk to resilience (Rutter, 2012; see p. 336), so too might autism research move from focusing predominantly on the negative consequences of compensation and broaden the focus to identifying factors that contribute to successful coping strategies. This in turn might be applied to interventions and supports for those at greater risk of maladaptive behaviour or negative psycho-social consequences.

While social interaction is crucial for humans and social isolation and loneliness is a problem for autistic people, findings from this program of study suggest that older autistic adults, driven by a strong preference for emotionally meaningful social interactions with close emotional partners, friends and family, might actively prune their social networks. This contrasts with the interpretations of other autism research findings (Hickey et al., 2018) and concerns more broadly about the implications of older autistic adults' already small, in some cases non-existent, social networks contracting further, and how best to address them. In the early 1980s identification of similarly shrinking social networks in typically developing older adults were thought to be a negative consequence of ageing, and interventions were developed and implemented to increase social interactions in aged care and other settings. However, there was minimal evidence of their effectiveness once the interventions concluded (Carstensen, 2021). Subsequently, a considerable body of work in this area – including the formulation of lifespan developmental models such as SST – revealed that a contracting social world was actually more likely to be associated with improvements in psychological wellbeing. Thus, if the patterns of social and emotional ageing in autistic adults are similar to those of typically developing adults, as the current body of research suggests is a real possibility, it will be important to avoid making similar assumptions about social isolation and loneliness in older autistic adults. For instance, supports that promote opportunities for making friends with other autistic individuals or seeking social engagement through autism community groups and online forums have been proposed (Lai & Baron-Cohen, 2015), but these solutions may not suit the specific needs, preferences, or stage-of-life of older autistic adults. Overall conclusions from the social instinct theme suggest the possibility that social ageing in autism is consistent with a lifespan developmental perspective and might align more closely in some important respects with normative development. This has the potential to open up a plethora of future research and clinical opportunities to assist autistic adults to negotiate the social world.

A prominent sub-theme in the qualitative analyses was resilience which is also strongly associated with lifespan psychology and is considered an important quality for successful ageing (Jeste et al., 2013). There is a need to better understand the protective factors that might lead to "resilient outcomes" in autism (Szatmari, 2018) and the analyses in the current work might help shed some light on this. All the participants in the current research program endured mental health difficulties, but still demonstrated 'better than expected' outcomes. Most participants demonstrated self-awareness, or at least the capacity to reflect on their thoughts and behaviours and identify ways to approach challenges differently in order to achieve a more positive outcome. There was also evidence of "social self-efficacy" in overcoming perceived adversity or barriers to achieving their goals. Most participants were driven by the desire to foster positive relationships with others and worked hard to address perceived weaknesses in this area. These individual characteristics are associated with resilience (Rutter, 2012). So too, and perhaps more importantly for autistic individuals (Lai & Szatmari, 2019), are systemic factors – family, supportive school experience and community engagement – all of which were common across the corpus. Charles' divergent experiences and less positive outcomes perhaps go some way to reinforcing the positive influence of these individual, family and environmental factors. Insights into patterns such as these might serve to reveal which and how individual and environmental factors play a role in building resilience that results in a relatively "happy autistic life" (Happé & Frith, 2020) and suggest avenues for further investigation.

The exploratory nature of qualitative research means it yields suggestive rather than conclusive results. It is hoped that the results from this program of research suggest new and potentially productive lines of research that broaden our understanding of autism and ageing. One approach might be to look to gerontology for well-conceptualised studies that can be adapted to autistic populations to test some of the theories proposed in this body of work. The need for more longitudinal studies in autism research is already well-known and much called-for, but taking a broad cross-discipline perspective could also be informative in terms of our work on the developmental (ageing) aspects of autism. Lifespan developmental psychology is a well-established area of research covering a vast range of aspects of ageing, including socio-emotional development. It seems logical that it would be a fertile field for inspiration on what and how to approach research on ageing in autism. It is acknowledged that the needs of autistic people are very likely different from typically developing older adults in many respects. There are, however, some fundamental similarities: just like autism, ageing itself is characterised by huge variability. It is also the case that while there are clear diagnostic characteristics of autism that set autistic people apart from neurotypical people, they do nonetheless pass through the same developmental age stages (e.g., toddlerhood, childhood, adolescence etc). Although the experience of these stages and transitions from one to the next can present additional and different challenges for autistic individuals (Lai et al., 2014), potential similarities might inform novel directions in our examination of the socio-emotional experience of autism in older adulthood.

Overall, it will be important to empirically investigate whether a lifespan developmental perspective really can inform our understanding of ageing in autism as this body of work suggests. Suggestions for ways in which future research might build on the findings of this research program are interwoven throughout the previous chapters, but specific research recommendations are summarised here as they relate to individual, social, and environmental or systemic level factors. Firstly, at the individual level, an obvious starting point is to investigate whether time horizons influence socioemotional goal priorities in later life in autistic older adults in the same way they do in the typically developing population (English & Carstensen, 2014; Sims, Hogan & Carstensen, 2015). In particular, whether the tenets of SST, the use of selectivity as an emotion regulation strategy, applies to older autistic adults is an area that warrants exploration. As discussed above the findings of this research program suggest that social selectivity may be an adaptive emotion regulation strategy in older autistic adults too, however it is not an option for people who are socially isolated or lonely, or who are unable to avoid negative situations (Charles, 2010) – scenarios that are particularly relevant to autistic people (Griffiths et al., 2019). Understanding the phenomenon of social selectively in autistic ageing might be especially helpful in identifying specific needs and appropriate supports; longitudinal studies that track within-individual changes in the size and composition of autistic adults' social networks over time could provide insight into the characteristics of older autistic adults' personal relationships and the role they play in emotional experience day-by-day and, longer-term, on overall wellbeing. Another potentially illuminating approach to investigating social and emotional ageing in autism is the use of experience sampling and ecological momentary assessment (EMA). Experience sampling enables the investigation of emotion regulation and aspects of social functioning such as quality and quantity of social interaction, loneliness, social motivation, empathy, and might more accurately assess the impact of these aspects of social and emotional functioning on the daily lives of autistic people of all ages, not just older adults. In geropsychological research, study designs that take account of the potential constraints that laboratory settings place on selection processes and resource availability in emotional development is considered critical for enhancing the ecological validity of findings and providing greater insight into the effects of context (Kunzmann & Isaacowitz, 2017; Springstein et al., 2022). The use of experience sampling to explore emotion regulation approaches and social experiences in typically developing older adults has provided greater clarity on the role of social networks in social and emotional functioning and identified distinct differences between how emotions are experienced and change in everyday life compared to in laboratory studies (Carstensen et al., 2011; English & Carstensen, 2014; Sims et al, 2015). These methods are beginning to be adopted in autism research (e.g., Gerber et al., 2019; Morrison, DeBrabander, Jones, Faso et al., 2020) although there are still few daily experience studies in autism. Using this methodology may better inform our understanding of social and emotional functioning in later life "in real time" – as it is experienced in the moment – so that more targeted and appropriate supports and interventions can be developed, but also to help identify changes in social and emotional experiences in autism in later life.

Selective information processing also supports socio-emotional goals in typically developing adults but although findings from this body of work suggest that there may be an age-related positivity effect in older autistic adults this needs to be empirically tested. Reliable and robust studies that have investigated the positivity effect in typically developing adults (Reed, Chan & Mikels, 2014) could be adapted to test whether older autistic adults also show an information processing bias, for instance in attention and memory, towards positive rather than negative information, compared to younger autistic adults. Investigating whether there are differences in preference for positive or negative information in older autistic adults compared to typically developing adults could also be useful in adapting and deploying existing effective tools and strategies for emotional regulation that are tailored to older autistic adults' developmental stage of life.

Empirical investigation of the possibilities as well as the potential limits of the lifespan developmental model of selective optimisation with compensation (SOC) and its applicability to promoting successful ageing in autism is also recommended. As a start, correlational and multimethod studies that have explored the relationship between SOC processes and indicators of successful ageing such as subjective wellbeing, positive emotional experience and loneliness, and shifts in goal orientation across adulthood (Ebner et al., 2006; Freund & Baltes, 1998; Freund, Napolitano & Knecht, 2017), could be adapted for use with older autistic adults. Fundamental to the SOC model of successful ageing is the maximisation of gains and minimisation of losses. Exploring goal orientation and how older autistic adults manage internal and external resources to balance gains and losses in later life could be particularly useful in building a picture of ageing in autism. But there may also be limits to the usefulness of SOC in autism. The pursuit of personal goals at the expense of sustainability, inability to flexibly adjust personal goals, and maintaining compensatory strategies that over time are too costly, are all problems of compensation that are of particular relevance to autistic individuals. Whether SOC is a model that can explain the prevalence of "autistic burnout" and mental health problems associated with autistic compensation or indicate strategies for managing over-compensation is worth investigating.

Secondly, at a social level, exploring the experiences and perspectives of older autistic adults' family members, close emotional partners and carers should be a priority. Qualitative research studies designed to explore their long-term first-hand experiences and insights into the social and emotional needs, and changes in the social and emotional functioning over the lifespan, of their autistic family member could reveal nuanced observations and suggestions for identifying, understanding and addressing potential risks and opportunities for successful ageing in autism.

At a structural or systemic level, there is an urgent need for better education of health professionals to ensure that interventions and supports are informed by evidence-based research rather than negative stereotypes and assumptions about ageing. Positive rather than negative messaging about ageing increases healthy behaviours in typically developing adults (Carstensen, 2021) and there is every chance that the same applies for autistic older adults. In ageing as in autism there is great heterogeneity and although more work is needed to ascertain the risks and opportunities for successful ageing in autism, it is vital that in the meantime healthcare models shift towards accommodating the desire for, and promoting, positive messages about autism and later-life autonomy and independence for autistic older adults. This can be achieved with training and targeted interventions that are person-centred and take into consideration person-environment fit and intrinsic capacity as mandated by the World Health Organization.

Finally, it is tempting to think the timing of increased awareness and research directed at ageing and autism is auspicious: it coincides with the UN's "Decade of Healthy Ageing 2021—2030", a global initiative endorsed by both the UN and WHO to ensure that the next decade is one of collaboration and action aimed at "improving the lives of older people, their families and their communities" (WHO, 2020; p. 2). Integral to this initiative is the empowerment and engagement of older adults whose experience can help achieve healthy ageing and improvements in wellbeing for all older adults, including those with disease and disability. WHO's ultimate aim is to transform policy and the engagement of service-providers with older people. This presents a crucial window of opportunity for autism researchers to do the same by informing themselves about, and indeed joining, this global initiative.

11.3 Limitations

There are limitations inherent in the methodological approach of this program of study. Firstly, although ideographic and intensive analysis of small and purposively selected homogenous samples is a hallmark of IPA methodology, the experiences and perspectives of autistic participants in this research program may not be generalisable to the wider autism population, particularly those older adults who have less adaptive functioning, cognitive impairment, higher levels of anxiety and depression, or low family support. However, such individuals may be less likely to volunteer in a study such as this making it challenging to explore their likely vastly different experiences. Moreover, how to find and engage with the many unidentified or non-identifying autistic older adults in the population remains a challenge. Indeed, the difficulties this relatively able group have had in terms of gaining a diagnosis and treatment support for mental health issues highlights the research challenge in identifying less able autistic individuals in community and clinical settings so that we can broaden our understanding of the social and mental health issues in older adults across the full range of the autism spectrum.

Related to this is that verification of some participants' self-reported formal autism diagnoses was not undertaken due to limitations to the scope of the research program. However, given that most of these participants volunteered the names and professions of diagnosing clinicians and the time-intensive nature of involvement in the study for no financial reward, reporting of false diagnoses was deemed unlikely. Similarly, anxiety and depression were necessarily self-reported by participants since the instances were historical rather than current reports. However, since the aim of the study was to explore the *experiences* of older autistic adults, self-identification of an autism diagnosis and mental health issues was in itself deemed fundamental to the study. Ironically, while the inclusion of self-diagnosed participants may be a limitation, including these individuals provides insight into the perspective of those very individuals who are less likely to present for clinical assessment (Brugha, 2018) and, but for this study, would have remained hidden members of the lost generation. Again, identifying those older autistic adults in the community who may not have a diagnosis, either because they do not wish to take that course of action or because they are simply unaware that they might be on the spectrum, is a challenge (Lai & Baron-Cohen, 2015). Disentangling the features of co-occurring and autistic conditions to arrive at a diagnosis based on behavioural assessments later in life, especially after a lifetime of practising learned compensatory and adaptive behaviours (Harmsen, 2019; Wise, 2019), is also challenging. The pathways to diagnosis experienced by all participants in this study further illustrates the complicated circular problem of identifying diagnosed older adults for research aimed at better understanding and meeting the needs of those same individuals who have difficulty in getting a diagnosis (Sonido et al., 2020).

Another limitation was that there was a potential for sampling bias in this study as the recruitment flyers did indicate that the study focus was older adults, changes over the lifespan and experiences of mental health issues. It is possible, therefore, that participants with mental health problems were more likely to volunteer, although mental health issues seem to be so ubiquitous in autism that a community sample from which participants with a mental health issue are excluded may in fact not be representative of autistic experience (Happé & Frith, 2020).

A final limitation of this study, and one that has been identified in other studies involving older autistic adults (Yarar et al., 2020), is that the results may reflect a "survivor effect" – another form of selection bias whereby only those adults who are functioning relatively well volunteer for studies such as this one. This issue has also been raised in respect of similarly unexpected findings in longitudinal studies on typical ageing (Carstensen et al., 2011) and refuted. It's possible that the patterns in social and emotional ageing and relatively positive outcomes identified in this program of work might be due to participants' higher abilities (Lord et al., 2022) but they may also be a valid if unexpected finding (as similar findings were when they first emerged in early studies on typical ageing (Carstensen 2021), even if it is inconsistent with researcher expectations based on autistic individuals' experiences at earlier stages of development. Thus, insofar as the participants in this research are a distinctly homogenous group in terms of age, stage of life, cognitive, social and communication abilities and skills, the socio-emotional and other patterns and trends identified in this body of work may be more representative of at least similar autistic older adults in the population than would be a more heterogenous sample.

11.4 Conclusion

In conclusion, Rutter's (2005) observation, based on a lesson learned from Leo Kanner, that it is important to consider given wisdom and prevailing theories with a degree of irreverence and to pay attention to phenomena that don't "fit textbook descriptions", is helpful in the context of how to understand the relatively good outcomes and positive outlook of the older autistic adults in this research program. That this group seems generally relatively satisfied with life certainly is not consistent with textbook descriptions, and seems to contradict, accepted notions and fears about the social and emotional difficulties associated with autism in later life, some of which might themselves be informed by negative stereotypes of ageing (e.g., Edelson et al., 2021; Michael, 2021; Rose & Michael, 2022). As noted above, similar findings in recent studies have suggested this anomaly is likely due to a healthy survivor effect (Tse, et al, 2022; Yarar et al., 2022), the implication being that this is the most plausible explanation for a trend that flies in the face of accepted expectations about both ageing and autism. But from both a developmental lifespan and a gerontological perspective, the findings of this research program are consistent with patterns of socio-emotional ageing seen in typically developing older adults which were also met with incredulity by researchers when evidence first emerged that contradicted the inevitability of decline and distress in older age (Carstensen, 2021). Thus this body of work offers an alternative perspective on the possibilities of ageing in autism, and also highlights that heterogeneity in autistic experience and needs likely extends across the lifespan (Lord et al., 2022).

In conclusion, through the voices of older autistic adults, this thesis provides context and insight into the perspectives and experiences of social and emotional functioning that might contribute to a more positive outlook in this relatively poorly understood stage of life in autism. Concerns about ageing raised in autism literature are based on extensive evidence for problems with social and emotional functioning in earlier life stages, but as studies on ageing in autism increase in number, we must be careful to challenge assumptions lest we miss opportunities to capitalise on findings, such as those presented here, that represent hope and developmental possibilities for successful ageing in older autistic adults.

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Appendices

Appendix A. Ethics Approval Documentation

The approval for this research program took place in 2016 under The University of Queensland's previous application process and therefore was conducted at the School of Psychology level. As such, the only formal documentation relating to the approval was email approval from the Ethical Review Officer who conducted the ethics review. A copy of this email is provided below.

Email approval

RE: Ethics Application

JS

Jeanie Sheffield <j.sheffield@psy.uq.edu.au>

☐

To:

- Ms Berthine Ommensen

Cc:

- Kate Sofronoff <k.sofronoff@psy.uq.edu.au>

+2 others

Tue 26/04/2016 12:09 PM

Dear Berthine

Thanks for such a thorough and well considered response to my questions. I have now reviewed all of the new materials you have sent and think you have done a great job of addressing all of the issues and providing the appropriate protection for all involved.

I think it is an excellent idea to seek information from as many sources as possible to try to establish a broader view of the experience of either having an ASC or being a family member or significant person in the life of the person with an ASC. My concern was only to ensure that the target person was fully aware of this and willing for the other person to discuss aspects of their life with you.

I am now happy to provide approval for the application subject to a couple of minor amendments:

On the information sheet under what is involved, please advise that the interviews will be recorded (by whatever means that is going to be done) and then when you say further on that recordings will be stored confidentially, you need to clarify whether the actual recordings will be retained and if so, for how long, alternatively if the recordings will be transcribed and the recordings then erased, you need to explain that. You may also want to explain that their real names will not be used when reporting any of their comments.

One final thing on the information sheet for the individuals with an ASC. There is a typo for the inclusion criteria on point 2: (also referred to as Asperger's syndrome or *Hugh* Functioning Autism).

Once you have made these corrections (and you do not need to send in any further materials), the approval number is: **16-PSYCH-PHD-29-JS**

All the best with the study. It is such an under-researched area and I think any data you collect will be fascinating and helpful.

Regards

Jeanie

Appendix B. Semi-Structured Interview Schedule

Ageing, Social Functioning, and Anxiety in Older Adults with High Functioning Autism Spectrum Conditions

Interview Schedule for Individual Participant

Demographic details

Name

Age (Date of Birth)

Education (e.g., highest level of schooling; highest level of tertiary education)

Employment status (current or previous)

Current living status

Prompt:

Independent

With family/carer (specify)

Relationship status (current/past)

Prompt:

Are you or have you been married/in a long-term relationship in the past?

Do you have children? How many?

Diagnosis (e.g., Autism Level 1, Asperger's Syndrome, PDD-NOS, etc.)
OR Self-diagnosed/identification

Age when diagnosed/self-identified

Support currently received

Prompt: social services, medication, therapy

A. History and Identity

1. Can you tell me a little about yourself, a brief history if you like, about your experience of life as someone with an autism spectrum condition?

Prompt:

When were you diagnosed?

How did your diagnosis come about?

How did you feel about your diagnosis at the time?

How do you feel about it now?

2. What does the term “Autism Spectrum Condition” (ASC) mean to you? How do you define it?

Note: substitute preferred term, e.g., ASC or Asperger’s etc

3. When you think of yourself as a person with an ASC, what are the characteristics that you see as strengths, and what aspects have caused you problems?

Prompt: Consider communication and social skills, life skills, interests, relationships, employment

B. Changes over time

4. How – if at all – do you think your ASC characteristics have changed as you have aged?

Prompt:

Consider particular time points: as a child; as a teenager; as a young adult; in your 30s, 40s, 50s; as an older person

What sort of things have become easier over time?

What has become more difficult?

(Can you be specific: which symptoms or characteristics?)

5. How has your life changed as you have grown older/aged?

Prompt:

Has there been a change (greater/less/no change) with regard to how you are now compared to how you were in the past in terms of:

- *Independence?*
- *Sense of belonging and acceptance?*

6. What aspects of life do you find most challenging?

Prompt: Social interaction, sensory issues, loneliness and isolation? Other?

7. What aspects of life do you enjoy or derive pleasure from?

Prompt: Special interest? Family? Friendships? Work?

C. Social interaction

8. Thinking about your life at the present time (*i.e., now*) how would you describe your experience of dealing with/getting along in social situations?

Prompt:

With family?

*With friends?**

With work colleagues?

With health professionals?

In unfamiliar situations?

** If you feel you have* no *friends: Would you like to have friends?*
**If you have friends: Tell me about your friends – do you have many friends? What things do you have in common/How did you become friends?*

9. How do you think your social interactions are different now compared to when you were younger? What has changed in the way you interact socially?

Prompt:

Consider particular time points: as a child; as a teenager; as a young adult; in your 30s, 40s, 50s; as an older person

What has become easier for you over time

What has become more difficult for you over time

- *Reading social cues?*
- *Joining and participating in conversations?*
- *Responding appropriately (choosing what to say and how to say it)?*
- *With family?*
- *With friends**
- *With work colleagues?*
- *With health professionals?*
- *In new or unfamiliar situations?*

D. Coping

10. How do you cope in social situations?

Prompt: Easily or with difficulty

11. What strategies do you use when you are in social situations/interactions?

Prompt:

Do you ever feel out of step in social situations/interactions and how do you deal with this:

e.g., special techniques, learned skills, avoidance

12. How do you feel after you have been in a social situation?

Prompt:

e.g., drained, stressed, anxious, tired ... relaxed, energised, happy?

E. Stress, anxiety, depression and worry

13. What situations or experiences make you feel anxious? What are the triggers?

Prompt:
e.g., Life transitions (e.g., relationship changes, loss or grief, new employment, retirement, ill health or medical issues, etc.)
Unfamiliar situations
Social situations
Timed tasks, etc.

14. How does/did anxiety affect your life?

Prompt:
General functioning

Relationships

Employment

Other

15. How do you experience stress and anxiety in a physical and psychological sense?

Prompt:

How would you describe your experience of feeling anxious?
e.g., Physical/bodily sensations,

e.g., Thoughts

16. How do you manage/cope when you are feeling anxious or worried about something?

Prompt: What coping strategies do you use?

17. Have you had professional help to manage your anxiety?

Prompt: medication, psychotherapy (e.g., CBT)

18. Have you experienced other difficulties with mood, such as depression?

Prompt:
Can you elaborate?

At what period in your life did you have depression?

What do you think triggered your depression?

Did you seek professional help to manage it? How did you manage it?

What effect does/did it have on your life? (e.g., general functioning, relationships, employment, other)

F. Recap – Reflecting on life's journey

19. Now that you are older, and can look back and reflect on life as an older person with many life experiences, how would you sum up your experience of life as a person with ASC?

G. Looking ahead to the future

20. What concerns, if any, do you have about getting older, and the years ahead?

21. What are you looking forward to in the coming years?

H. Is there something else we should know about?

22. Please elaborate on anything else you wish to share about your experiences of ageing on the Autism Spectrum …

Thank you for your time, and for sharing your experiences.