Strategies used by autistic adults to improve wellbeing: an exploratory mixed methods study in the UK

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A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Doctor of Philosophy

College of Health, Science and Society

February 2024

Abstract

The wellbeing of autistic adults has been largely ignored in the literature, but recently, neurodiversity-informed researchers have begun to ask autistic adults to define their experiences, needs, and self-managed strategies to improve and maintain their own mental health and wellbeing. Autistic adults report needing to spend time alone to recover from stressful experiences and poor mental health. This pragmatic PhD study, undertaken by an autistic researcher, sought (1) to find out how and where autistic adults in the UK might choose to spend this time, and (2) explore how this time benefits wellbeing. An exploratory sequential mixed-methods approach was used, and the research was supported by a community advisory group.

The qualitative analysis of interview data from autistic adults found that social environments can be highly overwhelming; alone-time may be used to retreat and recover from overwhelm, or 'recharge batteries' before re-joining the social world. Retreating requires feeling protected from the social and sensory world, while recharging tends to involve immersive or flow-state activities to feel self-regulated. Following alone-time, reconnecting with the social world may be desirable, but strategies may be needed to avoid future overwhelm. The statistical analysis of a two-part quantitative questionnaire survey for autistic adults described a wide variety of preferred alone-time environments and activities, but did not find clear statistical evidence of an association between the amount of alone-time wanted and/or spent and wellbeing. Recommendations for further research, policy and practice were generated by the community advisory group in response to the integrated qualitative and quantitative findings.

This is the first study that has sought to understand how self-managed time and space alone might benefit autistic wellbeing. The findings have implications for institutional structures such as healthcare, education and supported living, while challenging stigmatising misconceptions about autistic people's perceived anti-socialness.

Acknowledgements

Massive thanks to my supervisor team - Issy Bray, Felicity Sedgewick, Stuart McClean and Jo White - for seeing me through the PhD and for not being at all fazed by my refusal to be supervised in more conventional ways. Issy, I do not have the words to tell you how grateful I am that you were my director of studies. I could not have done this without your patience, kindness and humour. I hope we still get to have coffee and cake regularly.

Ruth Moyse, Michelle Parsons and Krysia Waldock, thank you for being my amazing community advisory group, I really hope that I have done justice in this thesis to your hugely valuable input. And a huge thank you to everyone I interviewed and everyone who filled in the questionnaires. May your retreat spaces always be restorative and your recharging processes bring you joy.

A heartfelt thank-you to the neurodiversity-led academics who have helped push ethical, divergent and inclusive theories and practices; in particular: Luke Beardon, Monique Botha, Robert Chapman, Damian Milton, Dinah Murray, Georgia Pavlopoulou, Amy Pearson, Dora Raymaker and Nick Walker. Your work has not only improved my research but helped me understand myself better:

I have been fortunate to have found two incredible neurosiblings who have been fantastic companions on my autistic autism researcher journey so far. Rhiannon Lloyd-Williams, my ND sister since soon after my autism assessment back in 2016, and Bethan Jones, the best PhD big sister I could hope for. Thank you both for your sage advice, virtual coffees, and sweary texts. I love you both.

Rebecca Reece, Ruben McNeil-Walsh, Samuel Baffour Kyei, and Yarden Woolf, I have loved sharing the PhD journey with you and am looking forward to waving my Pomodoro pom-poms at you from across the finish-line.

This thesis is dedicated to my beloved Simon, Maya and Lily, who know that even more than I love alone-time, I love to be with you, my most favourite people in the whole wide world.

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A note on chapter introductions

Please note that the short introductions to each chapter provide few or no citations. I made this decision to provide an accessible, visually uncluttered beginning to each chapter. However, all citable statements in the chapter introductions are elaborated on and fully referenced in the main bodies of each chapter.

Chapter One: Introduction

> "In my experience, people with autism tend to have their own timing, spacing, pacing and life-rhythm, so I interpreted autism as 'takiwatanga', meaning ‘their own time and space.'"
>
> - *Keri Opai (2017), originator of the Māori term for autism.*

This thesis details my exploration of self-managed time and space alone as a wellbeing strategy for autistic people. The study contributes towards a small but growing body of research describing how autistic people’s wellbeing needs and experiences do not always match those of non-autistic people. Such research suggests that approaches to support autistic wellbeing should be guided by autistic people themselves. I am autistic, and my neurodiversity-informed, mixed methods research was supported by a community advisory group of autistic people.

Autistic people have significantly higher risks of experiencing anxiety, depression, eating disorders, self-harm and suicidality, than people who are not autistic. Until recently, few studies sought to ask autistic people why these mental health risks might be higher; fewer still have explored autistic people’s positive experiences of mental wellbeing. As researchers begin to ask autistic people to define their experiences, needs and self-managed strategies to improve and maintain their own mental health and wellbeing, more complete understandings emerge. Autistic people describe how differences in how they experience the social and sensory world necessitate different approaches to improving wellbeing. One such approach, currently underexplored in the literature, is to spend regular time away from other people, in preferred spaces.

Understanding how self-managed time and space alone improves autistic wellbeing validates autonomous ways of living, has implications for institutional structures such as healthcare, education and supported living, and challenges stigmatising misconceptions about autistic people’s perceived anti-socialness. With the help of a community advisory group, my PhD research culminated in a set of recommendations designed to inform future policy, practice and research towards improving and maintaining autistic people’s wellbeing.

1.1 Background to the study

In 2023, a universal conceptual understanding of autism still proves elusive. Behavioural, biological and cognitive explanations do not consistently overlap; emic and etic perspectives appear mutually exclusive; and ever-changing definitions affect support, interventions and even human rights. Diagnostic definitions of autism reference atypicalities in social and communication behaviours, and the presence of restricted and repetitive behaviours (World Health Organization, 2018; American Psychiatric Association, 2013). However, autistic advocates argue that understanding the embodied autistic experience should be of primary importance in how autism is defined. Thus, it should be recognised that autistic people experience the world differently to people who are not autistic, due to differences between how both groups perceive and process sensory, communication and conceptual information (Ratto *et al.*, 2023; Williams, 2020).

Quantitative studies report a significantly higher prevalence of mental-health conditions (such as addiction, anxiety, bipolar, depression, eating disorders, obsessive compulsive disorder, schizophrenia, self-harm and suicidality) in the autistic adult population than in controls (Fombonne *et al.*, 2020; Hand *et al.*, 2019; Nimmo-Smith *et al.*, 2019; Cassidy *et al.*, 2018; Croen *et al.*, 2015). Qualitative and mixed methods studies show that the multiple factors negatively impacting the mental health of autistic people include stigma (Botha & Frost, 2020), limited specialist mental-health services (Maddox *et al.*, 2020; Unigwe *et al.*, 2017), differences in communication styles and contextual understandings between autistic and non-autistic people (Mitchell, 2021; Milton, 2012a); masking to hide autistic differences (Bradley *et al.*, 2021; Hull *et al.*, 2021; Cage *et al.*, 2019), and being in environments that trigger sensory sensitivities (Parmar *et al.*, 2021). As such, mental health interventions used in the general population may be less helpful in counteracting the negative impacts described above.

Further qualitative research shows that factors positively impacting the wellbeing of autistic people include autistic community connectedness (Botha *et al.*, 2022; Egner, 2022), stimming[1] (Crompton *et al*., 2020a; Kapp *et al*., 2019), autism acceptance (Cage *et al*., 2017), and engaging with areas of intense interest (Hickey *et al*., 2018; McDonnell & Milton, 2014). These studies suggest that supporting authentic autistic 'ways of being' may be more effective than wellbeing strategies developed for and recommended to a more general population.

Although anecdotal evidence suggests a range of wellbeing strategies that autistic adults enjoy and prioritise, there is a clear gap in the literature that explores strategies preferred by autistic people. One of the four themes identified for my Masters in Research (MRes) dissertation, "Autistics, autodidacts and autonomy: exploring how late diagnosed autistic women in the UK and US self-manage their health and wellbeing with dietary and other lifestyle measures" (Neville, 2019), was that of *Individual Environments*. I identified this theme from participants' descriptions of how finding or creating beneficial environments and routines for spending time alone was crucial for health and wellbeing; and it was a key inspiration for developing the research aim for my PhD.

1.2 Summary of the research

Research aim and questions

In response to anecdotal evidence that autistic people frequently need time alone to reduce anxiety, and with my MRes theme of Individual Environments (described above) in mind, my PhD originally aimed to explore this phenomenon in adults. I present my methods and findings from Chapters Three to Six but briefly outline them here. I used an exploratory sequential mixed methods design to qualitatively explore participants' needs and experiences, which then informed the development of a quantitative questionnaire survey. Contrary to my expectations, participants rarely mentioned anxiety in the qualitative interviews, but rather spoke of how time alone helped to alleviate overwhelm, and improve and maintain wellbeing. Following this finding, my study aim evolved from a focus on anxiety, to a focus on wellbeing (this evolution is discussed in detail in later chapters). The

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[1] 'Stimming' is the term given to a range of repetitive movements or actions used to soothe, focus, filter out sensory stimuli, relieve emotional distress and magnify positive feelings. 'Stims' include (but are not limited to) rocking, repeated finger movements, foot tapping, chewing pencils, playing with jewellery, and repeating preferred vocal sounds.

first phase of this study was a qualitative exploration of how, where and why autistic adults choose to spend regular time alone, by collecting interview data from 16 autistic adults. From this initial exploration the qualitative findings were used to develop a quantitative questionnaire which surveyed 267 respondents about what alone-time meant to them, and how and where they preferred to spend alone-time. 146 respondents also completed a second questionnaire which was compared with the first to look for relationships between alone-time and wellbeing. Integrating qualitative and quantitative phases in this way helped embed personal and cultural autistic experiences into the quantitative survey questions, and so increased the culturally and contextually sensitive nature of the overall study.

My final research questions (RQs) were:

RQ1: To what extent do autistic adults choose to create regular time alone?

RQ2: How and where do they choose to spend this time?

RQ3: Is there an association between using this time and space, and self-reported levels of wellbeing?

I answered RQ1 and RQ2 by collecting and analysing qualitative interview data, using Reflexive Thematic Analysis. I then developed a quantitative survey to quantitatively answer RQ2 and to fully answer RQ3. I analysed this data using (1) descriptive analysis to show which alone-time activities and spaces were felt most important to wellbeing, and (2) correlation analysis to look for associations between alone-time and self-reported wellbeing levels. Using both quantitative and qualitative methods facilitated comprehensive understandings of the phenomenon of autistic adults needing alone-time for their wellbeing.

Subjective understandings of autism, neurodiversity, and wellbeing

The concept of ‘autism’ is highly contested and the concept of ‘wellbeing’ is socially constructed; there are no universal agreements on what either word means or describes. I address historical and subjective understandings of autism in Chapter Two, but briefly outline conceptual issues here: with a lack of a clear biological or singular understanding of what autism is, epistemological differences in the concept of autism are grounded in whether the nature of autism is viewed as a collection of deficits or differences; whether autism is understood as a series of traits and behaviours or as a recognisable collection of experiences; and in terms of either ‘how the world experiences autistic people’ or ‘how autistic people experience the world.’ While we might consider autism to be objectively ‘real’, it can also be understood from a constructivist perspective, acknowledging that historical, social, political and cultural contexts shape our conceptual construct of what autism is (Ryan & Milton, 2023; Chapman, 2020a).

While a clinical diagnosis of autism demands evidence of atypicalities in social and communication behaviours and the presence of restricted and repetitive behaviours (World Health Organization, 2018; American Psychiatric Association, 2013), autistic people describe their embodied experiences differently, often with a focus on processing and reacting to social and sensory information in ways that contrast with how people who are not autistic process the same information. This divide in understandings will be discussed in Chapters Two and Three.

This shift in autism understandings has been at least partially led by the Neurodiversity Movement, a social justice movement born of the autism rights movement but which is inclusive of other neurodivergent[2] people. This movement, which seeks equality and societal inclusion for neurodivergent people, is based on assumptions that (1) the diversity among minds is natural and valuable, (2) that there is no ‘normal’ type of mind, and (3) that a neurodiverse society is subject to the oppression of social power dynamics, but would be more usefully embraced (Walker, 2021). These assumptions, which challenge earlier, pathological autism theories, have been crucial to the emergence of a gradual paradigm shift, through which the replacement of a formerly dominant conceptual framework creates change in outlook and practice (Cunningham, 2018). These assumptions are referred to as the Neurodiversity Paradigm, and will be discussed in Chapters Two and Eight.

While there is no singular definition of wellbeing, there are commonalities between understandings of the state and nature of wellbeing. However, wellbeing as a flexible state of feeling good and functioning well across a range of cognitive, emotional, and social domains appears to be a widely accepted and cross-disciplinary definition in the global North (Stewart-Brown, 2015; Black & Kern, 2020). For my mixed methods study, the concept

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[2] The term “neurodivergent’, coined by Kassiane Asasumasu in 2000, means having a mind that functions in ways which diverge significantly from dominant societal standards of ‘normal’ (Walker, 2021). Autism, ADHD and dyspraxia are just three of many types of neurodivergencies.

of wellbeing was not addressed during the qualitative phase, but was defined in the quantitative phase with the use of the Warwick-Edinburgh Mental Wellbeing Scale, a validated measure which aligned with the qualitative findings. The concept of wellbeing, and use of the chosen measure will be discussed in Chapter Five.

The concept of autistic wellbeing is, as discussed by Chapman and Carel (2022), somewhat of a Catch-22 situation for two reasons. The first is that dominant understandings of autism preclude the possibilities for being mentally well; thus, one can be autistic *or* one can experience wellbeing. The second revolves around a misconception that autistic people cannot truly articulate their own feelings; meaning that if they can verbalise their embodied emotional experience they cannot be recognised as autistic. However, autistic people, including those who have, since childhood, been considered 'severely autistic'[3] can and do articulate feelings of happiness and wellbeing.

This apparent Catch-22 is easily addressed through the Neurodiversity Paradigm. When autism is viewed through a neurodiversity lens, and autistic people's difficulties are understood through their differences and/or marginalisation rather than an inherent deficit; a state of wellbeing is no longer seen as something that can only be achieved by a person 'overcoming their autism'. Additionally, expressing wellbeing can be communicated through several means, whether through spoken words, augmentative and alternative communication tools, or behaviour, as long as the other person knows what to look for.

An interdisciplinary study

As will be discussed in Chapter Two, current understandings of autism at a conceptual level are interdisciplinary, combining ideas, theories and methods from several disciplines, particularly psychology and sociology (Arnold, 2023; Brownlow *et al*., 2023). Dominant autism theories were developed by psychologists, based on the earliest clinical descriptions of autism by psychiatrists, but more recently, sociologists and philosophers have offered a paradigmatic reframing of autism through neurodiversity and social disability theories (such as Milton 2012b; Chapman, 2020a).

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[3] The term 'severely autistic' is often used to describe a person who has consistently high support needs, uses little or no verbal speech, and/or is considered to be intellectually disabled. As autism is not experienced as a linear spectrum of normal-to-severe, the autistic community rejects this term.

Autistic wellbeing is a subject well suited to the discipline of public health. Although the multidisciplinary field of public health is not concerned with autism *per se*, it is committed to protecting and promoting the health and wellbeing of individuals and communities that are most likely to be impacted by health inequalities (McClean, 2020). Where bio-medical, psychological and sociological autism research seeks to define and explain autism and autistic people, public health concentrates on understanding and improving social determinants, such as the wider social and environmental contexts of health and wellbeing; and increasingly tackles the resulting inequalities through mixed methods research designs with a pragmatic focus (Bird, 2020). As will be seen in Chapter Two, the social determinants of autistic wellbeing have, until recently, been largely ignored by autism research (Pellicano & Heyworth, 2023).

As such, this thesis describes an interdisciplinary study grounded in the field of public health; it initially explores psychological and sociological theories of autism and autistic wellbeing but uses qualitative and quantitative methods to describe barriers to and supports of autistic wellbeing within a socio-ecological context (i.e. recognising that the interaction of individual characteristics and social structures underlie health outcomes. Golden & Earp, 2012). This approach to integrating pre-existing disciplines and translating research findings into pragmatic solutions addresses the inherent dual research/practice nature of public health (Gauffin & Dunlavy, 2021).

Positioning

Seven years ago I was assessed as being autistic. To me this was simultaneously shocking, in that I had not considered that I might be autistic until mere weeks before the assessment; and unsurprising, in that I had always known that I did not experience life as other people seemed to. Within months of my assessment I had joined a global online community of autistic adults and noticed a profound shift in terms of a previously lifelong sense of feeling ‘othered’ and ‘strange’ to experiencing a new and empowering sense of ‘belonging’ and ‘normal’. Far from the public perception of autism as a tragic lack of empathy and social functioning (Nordahl-Hansen *et al.*, 2018; Fletcher-Watson & Happé, 2019), I met autistic people who were warm, funny, creative and highly empathetic. Autistic people of all nationalities, skin tones, genders, ages and social standing; artists, writers, computer programmers, musicians, business owners, academics, shop workers, teachers and doctors;

extroverts and introverts; people with varying and fluid states of physical health and/or disability. As an added bonus, I also learned that my need for frequent time alone, without which I felt anxious, exhausted and prone to emotional outbursts, was reflected in the experiences of many others in my newfound community.

A few years later, the late-diagnosed women I interviewed about their self-managed health and wellbeing strategies for my MRes dissertation research described spending time resting or being creative in preferred environments in more detail than the dietary and movement practices that I had expected (Neville, 2019). Following this research, discussions with autistic friends and colleagues helped me to identify how time alone as a self-managed wellbeing strategy for autistic people is currently underexplored and would be a useful, potentially impactful area of research, which could be well-served by a PhD structure. As such, writing in first-person for this thesis signals that I am situated within this research: the aims and research questions stem from my own needs and experiences, and, in turn, the research findings have impacted my own understandings of wellbeing as an autistic adult. Reflexivity and my positionality as an autistic autism researcher will be more fully discussed in Chapters Three and Eight.

Language

Language conventions around autism and autism research differ according to whether autism is considered to be a medical disorder or a neurological difference. As I show in Chapter Two, the first is informed by the medical paradigm which assumes one 'healthy' presentation of neurological functioning and behaviour; while the second is informed by the Neurodiversity Paradigm which embraces diversity among minds. As my personal and academic understandings are firmly grounded in the Neurodiversity Paradigm, some of the language used in this thesis may be new or oppositional to that of the reader's; where I believe that the language I use may be contentious, I explain my choice of words. Where I have used terms commonly used in autistic and otherwise neurodivergent discourse but less well known in academia, I provide descriptions in footnotes. However, as neurodiversity informed language and terminology is new and evolving it should be understood that the description of such terms reflect common understandings at the time of writing and should not be taken as static and final. In particular, while person-first language (i.e. person *with* autism) is commonly used in the literature, this thesis uses identity-first language (i.e.

autistic person) as this is the most endorsed preference of the autistic community (Bonnello, 2022). I also avoid using the terms Autistic Spectrum Disorder (ASD) and Autistic Spectrum Condition (ASC), as neurodiversity-informed theory does not consider autism to be a disorder or a condition.

Implications of researching during the COVID pandemic

I had already planned to use online methods to elicit qualitative and quantitative data before the COVID-19 pandemic began. As such, no adjustments to the proposed data collection methods needed to be taken as a result of lockdown or social distancing restrictions. However, it is important to recognise that the findings may have been different had the research taken place before the UK pandemic restrictions, due to participants' recent experiences of lockdowns, social distancing and mental health. Without collecting data before the pandemic, and without similar studies to reference, it is not possible to tell with certainty what differences might have occurred in either the qualitative or quantitative data. However, a number of studies, looking at how the pandemic affected autistic people's mental health experiences, suggest a combination of positive and negative effects which closely relate to this study. While autistic people enjoyed a reduction in conventional social challenges, an increase in control over the sensory environment, and more time to engage in interests during lockdowns; reduced access to support services, less opportunity for time alone and fewer opportunities for embodied, physical social experiences contributed towards poorer mental health (Bundy *et al.*, 2022; Pellicano *et al.*, 2022a; Heyworth *et al.*, 2022). These aspects will be discussed in Chapter Four.

From a personal point of view, I began my PhD, on the autistic need for time alone, in the Autumn of 2020, six months into the UK restrictions and closures. From having previously had space to myself for work and recreation for six hours a day, five days a week; I now variously had up to three family members working or schooling at home with me during those same hours, leaving me with little space to self-regulate in the ways that I needed to. As with countless other households locally, nationally and internationally, balancing the diverse needs of four family members constrained within a small house became a juggling act. The irony of beginning research on the importance of time alone for autistic people during a time when I, an autistic person, had not had access to this time for several months was not lost on me. However, noting how difficult it was to focus on reading, retain information, write with any degree of fluency, or to think creatively at the outset of my PhD, meant that I was also able to observe those temporarily lost skills gradually returning as, one-by-one, family members returned to school and work for increasing amounts of time. As such, while my research aims, questions and methods were unaffected by the pandemic, my own experiences will have undoubtably yet unmeasurably influenced my relationship with the study as a whole.

1.3 Thesis structure

This thesis details the research I undertook in a chronological order. Immediately following this introductory chapter, I discuss how the literature reflects understandings of autism and autistic wellbeing over the past eighty years, covering (1) a historical overview of definitions and theories about autism, (2) a review of papers discussing autistic mental health, (3) an exploration of how emancipatory research has changed our understandings of autism and autistic people, and (4) a discussion of recent research and initiatives into autistic mental health and wellbeing, based on embodied understandings of autism.

The middle four chapters make up the methodology, methods, results and discussions of the qualitative and quantitative phases. Chapter Three describes my positionality, my pragmatic approach, how and why I worked with a community advisory group, and a justification for the mixed methods study design I used. It then details how I undertook the qualitative phase of this study, from ethical considerations through to analysis. Chapter Four details my qualitative findings and discusses the four themes that I identified in the data. The fifth chapter describes how I undertook the quantitative phase of this study, from ethical considerations through to analysing the data. Then, in Chapter Six I present and discuss my quantitative results before discussing the interpretation of the mixed methods research phases.

The penultimate chapter describes outputs from the research: how recommendations for policy, practice and further research were developed with the community advisory group, further practical strategies to improve autistic wellbeing, based on the qualitative phase; and ethical research dissemination considerations. Chapter Eight, a more reflexive chapter, concludes the thesis: I summarise my findings in the context of existing literature and discuss methodological and personal reflexive conclusions on my PhD study in its entirety.

Chapter Two: Literature Review

> "Autistic academic life: Look in academic paper release lists. View the introductions. Observe the words 'disease' 'disorder' 'deficit', in paper after stigmatising paper. Shake head, in a disappointed way. Make cup of tea. Go into garden."
>
> - *Anne Memmott (2022), autistic researcher (via Twitter).*

Dominant understandings of autistic wellbeing are contentious, and dependent on epistemological framings of autism itself. Further, literature searches using terms such as 'autis*', 'wellbeing', and 'adults' are dominated by papers describing research on the wellbeing of parents, carers and support workers of autistic children. Thus, rather than structuring this chapter around a systematic review, or setting out to critically appraise specific relevant papers, I designed this chapter to (1) reflect the inclusive approach I took in selecting literature which guides understandings of autistic wellbeing, and (2) critiquing theories and assumptions in the literature made about autism, autistic people, and autistic wellbeing. This literature review sketches a history of autism and autistic wellbeing research, showing how autism concepts and theories have a strong influence on research designed to understand and improve the wellbeing of autistic people. This review is organised into four parts:

1. A historical overview of early objective descriptions and theories influencing how we know what we think we know about autism: an explanation of how bias has led to misunderstandings about autism and autistic people, and an introduction to the social theory of disability and the neurodiversity paradigm
2. Current understandings about autistic adults and their mental health: a review of papers that talk about poor autistic mental health and offer explanations for the high rates of poor mental health conditions such as anxiety, depression and suicidality; and an exploration of links between those rates, the medical framing of autism and public perceptions of autism.
3. An exploration of what emancipatory approaches bring to autism knowledge: how listening to autistic accounts about the experience of being autistic, particularly

though autistic scholarship and participatory research, changes our epistemological understandings of what autism is.

4. The existing research on autistic wellbeing: an exploration of how understanding autism from the autistic experience changes how we comprehend autistic mental health; and a critical discussion of what changes can be and are being made to improve mental health and wellbeing for autistic people.

2.1 Autism discourses and praxes

The concept of autism is hotly debated within research and praxis, and so it is important to understand how varied current perceptions of the aetiology of autism have been influenced by historical, theoretical and cultural perspectives. These perspectives have shaped autism research over the past few decades, resulting in highly contradictory 'knowledge' about autism and autistic people. Without unpicking these, it would be difficult to understand how or why mental health and wellbeing interventions for autistic people may or may not be effective.

Infantile Autism, Autistic Psychopathy and Asperger's Syndrome

Leo Kanner's clinical observations of children in the 1940s are responsible for some of our earliest academic understandings of autism. Kanner observed a group of 11 children, in an American psychiatric hospital, who showed similar features, such as preferring to be alone, having a hyper-sensitivity to stimuli, and displaying repetitive movements. He saw what he termed *infantile autism* as a disorder *"characterized by extreme aloneness and preoccupation with the preservation of sameness"* (Eisenberg & Kanner, 1956, p.565). Kanner's early research, and his subsequent 'Early Infantile Autism' diagnoses of over 120 children, influenced the second edition of the Diagnostic and Statistical Manual (DSM-2, 1952) definition of autism as a form of childhood schizophrenia marked by a detachment from reality.

Although Kanner claimed not to have heard of Hans Asperger's earlier work, which was largely undiscovered outside of Germany until the 1970s, recent research has uncovered evidence that he was well aware of Asperger's observations of children in his clinic, whom he described as having 'Autistic Psychopathy' (Czech, 2018). Many of Asperger's published observations (1944, *translated* 1991) are similar to Kanner's: lack of eye contact, social withdrawal, speech and movement differences, resistance to change, pursuing of special interests to the exclusion of all else. However, there are key differences: where Kanner saw rote learning and a lack of language, Asperger noted fluency of language, originality and creativity. The following context may have given rise to these differences: Kanner was the founding director of a child psychiatry programme and Asperger had a complicit diagnostic role within the Nazi eugenics' regime through which children considered not to be of use to society due to 'mental retardation' (therefore likely those not meeting his standards of language and creativity) were either sterilised or sent to be euthanised (Czech, 2018).

Following the work of Kanner and Asperger, research into the aetiology of autism did not progress much until the 1970s when Lorna Wing, a proponent of Asperger's autism research if not his politics, carried out a study of children in London with Judith Gould. This large-scale epidemiological study explored "*The relationships between mental retardation, typical autism and other conditions involving social impairment*" (Wing & Gould, 1979, p.11). Wing and Gould subsequently categorised three main 'features' of autism: difficulties with social interaction, communication and imagination. These features were later to become the 'triad of impairments' used in the DSM-3 (1980) which established autism as a diagnosis separate from schizophrenia, describing it instead as a Pervasive Developmental Disorder. Wing also coined the term 'Asperger's Syndrome', which she included alongside the category of Early Childhood Autism to create the concept of an autism spectrum (Wing, 1981). However, sub-classifications such as Asperger's Syndrome were later discontinued from DSM-5 and the International Classification of Diseases (ICD)-11 (American Psychiatric Association, 2013; World Health Organization, 2018), in part due to a lack of meaningful differences in the criteria leading to insufficient standardisation in diagnoses (Fletcher-Watson & Happé, 2019).

Electric shocks, empathising quotients and extreme male brains

Autism literature since Kanner and Asperger has largely been concerned with describing, preventing or curing the perceived deficits of autism (Pellicano & den Houting, 2021), but framing autism as a collection of deficits can be seen as ethically problematic. Attempts since the 1970s to identify a distinctive genetic marker or specific cause of autism (so far inconclusive, Parallada *et al*., 2022) have diverted resources away from existing autistic people and their own health and wellbeing priorities (Pellicano & den Houting, 2021). Botha and Cage's (2022) survey of autism researchers' construction of autism found that over 60% of participants expressed "*cues of ableism… conceptualised as dehumanization, objectification, and stigmatization*" (p.16). In turn, psychological explanations of perceived autistic cognitive deficits have influenced public understandings of autistic people as being cold and unemotional, which likely influences how autistic people are treated both socially and institutionally. Research with autistic adults who experienced training in childhood to reduce 'autistic behaviours' indicates painful lived experiences and long-term trauma (Anderson, 2022; McGill & Robinson, 2020; Kupferstein, 2018).

Ole Ivar Løvaas, who wanted "*to be remembered as one who worked to free those whose minds enslaved them*" (The Løvaas Centre, 2013), introduced behaviour modification for autistic children in the 1950s. His Applied Behavioural Analysis (ABA) was based on intensive behavioural training methods originally developed with animals and included the use of electric shocks, slapping, and withholding of food to encourage eye-contact[4] and verbal communication, and to discourage self-injurious behaviours and crying (Løvaas *et al*., 1973). Modern ABA practitioners distance themselves from more aversive methods, arguing that their gentler behavioural conditioning methods enable autistic children to communicate, learn basic self-care and manage disruptive behaviour during intensive, 25-40 hours weekly training programmes (Smith, 2012). However, qualitative work with autistic young adults who received ABA in the past 25 years found that, at best, participants felt the therapy to be useless and, at worst, they felt that the process was traumatising, humiliating and dehumanising and that it denied them bodily autonomy (Anderson, 2022). Behavioural conditioning practices for 'normalising' the behaviour of autistic people includes the use of contingent electric skin shock devices on autistic and other developmentally disabled students at the Judge Rotenberg Center, Massachusetts, and is still practised after twenty years despite being condemned for torture by the United Nations Special Rapporteur on Torture (Zarcone *et al*., 2020). Research into the methods of and perceived benefits of ABA for autism still continues despite failing to address arguments against its use, such as a lack of understanding the reasons for why autistic people may behave a certain way, and a lack

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[4] Making eye contact is uncomfortable and stressful for many autistic people, and uses up cognitive resources. (Jaswal & Akhtar, 2018).

of data for either short-term or long-term effectiveness (Tsiplova *et al*., 2022; Sandoval-Norton *et al*. 2021).

Psychological research since the 1980s has centred around cognitive testing designed to identify and explore perceived core-deficits such as Theory-of-Mind (ToM). Using the ToM model originally developed in studies with primates (Premark & Woodruff, 1978), psychologists Baron-Cohen *et al*. (1985) and Leslie & Frith (1988) proposed that autistic people lack the ability to detect, interpret or understand the mental states of others. Researchers extrapolated that lacking ToM evidenced reduced empathy, and so the Empathising Quotient, a self-report measure developed by Baron-Cohen & Wheelwright (2004), became frequently referenced in the literature, reinforcing the idea that a lack of empathy is a central feature of autism (Fletcher-Watson & Bird, 2020). Although current literature points to flaws in the construction and application of such core-deficit models, ToM remains a recurring and pathologising theme in autism research (Astle & Fletcher-Watson, 2020), raising questions around empirical claims and societal harms caused (Gernsbachr & Yergeau, 2020).

During development of their Empathising Quotient, Baron-Cohen & Wheelwright found that (1) autistic people score lower than people who are not autistic, and (2) women in the general population score higher than men. In light of these findings, Baron-Cohen *et al*. argued that autistic deficits in empathy could be understood within an 'Extreme Male-Brain' (EMB) type, a combination of poor empathising, but superior skills in systemising - described as a strength in or drive to analyse and construct systems (2002). Two key criticisms of the EMB theory are (1) that gendered accounts of personality traits are based in cultural ideology (Milton, 2017), and (2) that the effect of such research may inadvertently favour boys and men in future diagnoses, thus further reducing the likelihood of support for autistic girls and women (Krahn & Fenton, 2012).

Diagnostic bias: gender, ethnic and cultural autistic representations

Autism diagnostic tools such as the Autism Diagnostic Observation Schedule (ADOS, Lord *et al*., 2000) draw upon historical perceptions of stereotypical autistic behaviours in relation to ideas of appropriate social behaviour; while self-selecting items from Baron-Cohen's *et al*. Autism-Spectrum Quotient (AQ, 2001) were developed from domains in Wing & Gould's

(1979) triad of impairments as discussed earlier. As such, autism diagnoses depend on individuals displaying behaviours or traits historically observed in other autistic individuals. A key problem here is that the autistic individuals observed have historically been white, middle-class boys and young men in Western cultures and so the diagnostic criteria is not fully inclusive of other demographics. For example, Carruthers *et al*. (2020) study on autism screening across India, Japan and the UK demonstrated differing cultural understandings of traits. 'Doing things spontaneously' was a predictive item in the UK sample but not in Japan or India; and 'when s/he talks, it is not always easy for others to get a word in edgeways' was only predictive in the Japanese sample. Further, autistic girls tend to score lower on assessment measures; they display less restricted and repetitive interests and behaviours and tend not to be identified and referred for diagnosis unless they are displaying higher emotional and behavioural problems (Duvekot *et al*., 2017; Frazier & Hardan, 2017). Not taking such differences into account leads to bias in the identification and diagnosis of autistic individuals, causes representational challenges in research, and indirectly creates inaccurate and stigmatising stereotypes (Waldock & Keates, 2023; Giwa Onaiwu, 2020a; Botha *et al*., 2020).

Autism has historically been considered a predominantly male phenomenon; Asperger viewed the autistic personality as an extreme variant of male intelligence (1944), and Baron-Cohen's widely accepted EMB theory (2002 & 2017) strengthened this opinion in academia and public perception. A review of around 24,000 articles in UK papers between 2010-2020 found that the terms 'autistic' and 'autism' are used in connection with boys twice as often as girls, and are 4.6 times more likely to be used in connection with sons than daughters (Karaminis *et al*., 2022). The autistic male to female ratio is currently estimated to be 3:1 (Loomes *et al*., 2017) and, as biological research has not yet found a definitive explanation for this bias, social research suggests four linked concepts: (1) that research to date, and thus public perception of autism, has historically been based in a male-centric conceptualisation, preventing girls and women from being easily identified and put forward for diagnosis (Cascio *et al.,* 2021a; Tint *et al*., 2018; Kanfiszer *et al*., 2017), (2) that diagnostic tools are biased towards males, leading to diagnosticians either withholding a diagnosis or misdiagnosing females with other conditions (Leedham *et al.*, 2019; Duvekot et al., 2017; Frazier & Hardan, 2017), (3) that girls and women are more socially motivated and so likely compensate for and mask autistic characteristics, which reduces the chances of being identified as autistic (Hull *et al.*, 2020; Bargiela *et al.*, 2016; Sedgewick *et al.*, 2015), and (4) that the autistic population shows a high proportion of genders that do not fit the binary model, and that this is not reflected in the literature (Warrier *et al.*, 2020).

Studies into racial disparities in the identification of autistic children note that, in countries such as the UK and US, autistic children who are not white are more likely to be mislabelled with behavioural or language difficulties (Constantino *et al.*, 2020; Dababnah *et al.*, 2018; The National Autistic Society, 2014; Mandell *et al*. 2009). Although a cohort study of over 7 million English children in state funded education suggests that there has recently been a higher prevalence of autism diagnoses among pupils from ethnic minority and immigrant backgrounds (Roman-Urrestarazu *et al.*, 2021), it will likely be some time before the gap closes between white autistic diagnosed adults, and autistic diagnosed adults who are not white. This will have an effect on research findings; a 2016 review indicated that of the 28% of articles adequately reporting the race and ethnicity of participants, participants were overwhelmingly white (West *et al*. 2016), and a 2021 review highlights a major neglect in reporting black autistic women and girls in autism research, discourse, policy and practice (Lovelace *et al.*, 2021). Cascio *et al*. (2021a) note that autistic participants' experiences of racialisation can create a double minority status, meaning that certain experiences of autism are underrepresented when participants who are not white are excluded. An additional factor contributing to culturally unrepresentative autism research is created by reduced involvement from ethnic minority families, who report that barriers are created by stigma, cultural distrust of research and inaccessible research materials (Shaia *et al.*, 2020; The National Autistic Society, 2014). To reduce such disparities, Malone *et al*. (2022) call for inclusive research which centres black autistic voices throughout the research design, while Jones and Mandell (2020) make a clear argument for actively recruiting, developing and supporting black students and trainees to create the next generation of scientists and practitioners in the autism field to better support the needs of black autistic individuals.

Currently, a clinical self-report measure is in development which considers autistic traits as described by autistic people. Development of the Self-Assessment of Autistic Traits (SAAT, Ratto *et al.*, 2022) has engaged autistic people from diverse backgrounds, prioritised autistic perspectives and highlighted the impact of social structures on autistic people. The SAAT comprises four overarching domains, which together describe sensory and motor experiences, strengths in identifications and patterns of details, and developing deep knowledge, the unique ways that autistic people communicate and interact socially, and the ways in which autistic people experience and navigate the world and their personal lives. Unlike traditional autism screening tools, the SAAT is inclusive of diverse gender, ethno-racial, disability and educational experiences, and thus avoids many of the biases described so far in this chapter.

Autism prevalence

Estimates for autism prevalence vary considerably; Zeiden's *at al*. (2022) systematic review of 99 prevalence estimates in 34 countries found a range of 1.09/10,000 to 436/10,000, with both global and European medians of 100/10,000. There are several reasons for discrepancies between estimates, and these are usually due to how the autistic demographic is identified. For instance, Brugha's *et al*. 2012 study for the NHS (which informs the oft-cited 1.1% UK figure) predated the DSM-5 (American Psychiatric Association, 2013) and ICD-11 (World Health Organization, 2018) criteria which newly included autistic people without intellectual disabilities. Considering that NHS England's recent report of autistic people known to GPs shows only 14.15% of identified autistic males and 15.36% of identified autistic females as also having learning disabilities (NHS, 2022), 1.1% would appear to only represent the tip of the metaphorical iceberg.

Prevalence studies tend to report on autistic children, which would reflect people of all ages if it wasn't the case that many autistic people are not identified or diagnosed until adulthood. This would perhaps indicate that childhood prevalence estimates reflect, at best, a minimum prevalence. Recent NHS data records of autistic people known to GPs show much higher numbers in children and young adults; after the age of 34, figures drop sharply; diagnosed autistic males aged 18-24 account for 3.04% of the population, dropping to the age bracket 25-34 accounting for 1.11%, and males aged 34-44 only accounting for 0.36% (NHS, 2022). Records of children tend to be based on diagnostic records; however, missing GP data and long waiting times for diagnoses make absolute prevalence rates difficult (Russell *et al*. 2022). Crane's *et al*. (2016) study of 1,047 families with an autistic child showed that, on average, parents waited 3.5 years from the point at which they discussed concerns with a health professional to gaining a clinical diagnosis. The UK Cohort

Millennium Study found that factors such as low socio-economic status, a lack of parental concern over socio-behaviours, and no cognitive delays, all increased the chance of a later diagnosis (Hosozawa, 2020). Further discrepancies between diagnostic rates in the UK are apparent when comparing, for instance, the 4.7% of school aged children in Northern Ireland who have a diagnosis of autism (Rodgers & McCluney, 2022) with the 1.76% of school aged children in England with a diagnosis of autism (Roman-Urrestarazu *et al.,* 2022).

Meanwhile, 4.37% of 10-17 year old boys and only 1.39% of 10-17 year old girls are recorded as autistic on GP registers in England (NHS England, 2022), demonstrating how gender disparities in identification and diagnosis are apparent from childhood. Age and gender discrepancies are partially described in Russell's *et al*. (2022) UK cohort study which reports a 787% increase in autism diagnoses between 1998 and 2018, with adults, women and 'higher functioning'[5] individuals showing particular rising diagnoses. As discussed earlier, being identified and referred for a clinical diagnosis is less likely for women and for people of colour, meaning that many autistic adults are either unaware of their autistic identity, or are dismissed for referral by GPs who do not have suitable training to recognise autism. In 2020, only 1.23% of males and 0.39% of females were registered as autistic with GPs (NHS, 2022). Therefore, autistic people who (1) are unaware that they might be autistic, (2) who are waiting for a diagnosis, or (3) who self-identify or have been privately assessed as being autistic and so not added to GP lists, are all excluded from prevalence estimates. The 2020 UK census (Office of National Statistics, 2020), which suggests a 2.9% autism prevalence, only offered an 'autism tick-box' to 16-64 year olds who stated having a physical or mental health condition lasting 12 months or more; as such, this figure can only tell us how many people with a physical or mental health condition identify as autistic.

The social theory of disability

Dominant autism discourses, such as those which give rise to behavioural training and medical interventions, develop deficit-based autism knowledge within what Walker (2021) refers to as a 'pathology paradigm', a paradigm reliant on the medical model of disability,

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[5] Higher functioning is a term often used for autistic people with an average or above-average IQ, or who are verbal, or who do not consistently have high support needs. The autistic community rejects this term as it (1) does not consider variable support needs, (2) using spoken words is not consistent with cognitive ability, and (3) using 'high functioning' or 'low functioning' terminology is divisive.

and which approaches autism as a disability primarily rooted within individuals (Pellicano & den Houting, 2021). The pathology paradigm relies on the prevalent set of assumptions and practices that construe neurotypical - or cognitively typical - ways of understanding and being as healthy; and atypical ways of understanding and being, as disordered (Catala *et al*., 2021; Walker, 2021; Pellicano & den Houting, 2021). Most autism research and praxes still consider that eradicating, curing or overcoming 'Autism Spectrum Disorder' or making autistic people behave more like people who are not autistic are key goals (Pellicano & den Houting, 2021; Ne'eman, 2021). However, the focus on interventions and the nature of interventions within this paradigm shows a lack of understanding for autistic lived experiences, as many problems experienced are due to external barriers, rather than an impairment located within the person (Walker, 2021; Chapman, 2020b; Hersh *et al*., 2020).

Within the social model of disability, external physical and social barriers are considered in how they limit an individual from taking part in communities on an equal level with others (Oliver, 1998). While Oliver, who introduced the concept of the social model of disability in the early 1980s, did not claim that the social model would be an all-encompassing framework, he did consider that professionals might use it to reframe their practices to make them more relevant to the needs of disabled people (Oliver, 2013). Chapman (2021, p. 1368) describes how research within the social model of disability replaces the question "*What is wrong with this individual or group in relation to those who are normal?*" in favour of "*How can we understand the strengths, limitations, struggles, or potential of this group or individual in the wider social context?*"

The Neurodiversity Paradigm

In direct contrast to the pathology paradigm, the Neurodiversity Paradigm recognises the dynamics of social power inequalities, privilege and oppression over neurodivergent people, and considers that diversity among minds is natural, healthy and valuable (Walker, 2021; Walker & Raymaker, 2021). The term neurodivergent, as coined by Asasumasu in 2000, is a non-diagnostic and value-neutral term describing a person whose cognitive processes, and thus behaviours, are distinctive from the majority or dominant cultural standards of cognitive functioning and behaviours (Walker, 2021). Autism, ADHD, dyslexia, bipolar and Tourette's are considered to be innate forms of neurodivergence and present from birth;

while acquired forms may result from extrinsic events such as trauma or long-term brain-altering medication use (Walker, 2021).

The neurodiversity movement - a social justice movement seeking civil rights, equality, respect and full societal inclusion for neurodivergent people - challenges the medical model's pathologizing of minority cognitive styles and argues for a reframing of neurocognitive diversity (Walker, 2021; Chapman, 2021). Sinclair is considered to be a major influencer of the movement following their seminal presentation “Don't Mourn for Us” (1993); and through activist work framing how reshaping societal expectations and norms would create a better world for autistic people (Pripas-Kapit, 2020). The concept of neurodiversity developed and spread during the 1990s through several global communities of autistic adults. During the early days of email-based discussion groups, these adults found safe spaces online to gather socially, debunk autism misinformation, and provide support through political advocacy (Walker & Raymaker, 2021; Dekker, 2020; Tisoncik, 2020; Sinclair, 2010; Kras, 2009). Even now, social media platforms offer a wealth of intersubjective knowledge from neurodivergent communities, which otherwise might not be readily available to researchers who are not autistic or otherwise neurodivergent (Bertilsdotter Rosqvist *et al*., 2022).

Critics of the neurodiversity movement argue that its aims exclude those who are unable to communicate through social platforms and discussion forums. Indeed, Singer, who is commonly credited with coining the term ‘Neurodiversity’ since being the first person to publish using that term, referred only to ‘high-functioning autistics’ (Singer, 2017). However, advocates of the neurodiversity movement consider that neurodiversity applies to a range of neurotypes[6], with no one style of neurocognitive functioning or level of support needs considered more or less valid than others (Milton, 2020; den Houting, 2019). A particular strength of the neurodiversity movement has been the increase of advocacy from within (den Houting, 2019). Advocacies include creating physical inclusive autistic spaces (Buckle, 2020), facilitating participatory research (Raymaker, 2020), consulting on the revision of autism diagnosis in the DSM-5 (Kapp & Ne'eman, 2020), actively working to ban the use of electric shock devices at the Judge Rotenberg Center (Neumeier & Brown, 2020), and raising

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[6] Neurotype is a category distinction separating different neurodivergent and neurotypical people (Fletcher-Watson *et al*. 2021).

the profile of autistic people of colour (Giwa Onaiwu, 2020b). Further, members of neurodiversity groups such as The Autistic Self-Advocacy Network (ASAN) include intellectually disabled autistic people, those who cannot live independently, survivors of institutions, and users of Augmentative and Alternative Communication (Ne’eman & Bascom, 2020).

This first section of my review has briefly summarised nearly 80 years of research debating what autism is (or might be), deciding how autism and/or autistic people should be treated, defining who gets to be diagnosed as autistic, and thus determining who should be represented in autism research. Against this backdrop of such varied historical, cultural and theoretical understandings, it is not particularly surprising that very little research has been carried out into the health and wellbeing of autistic people. However, in the past decade, research has begun to consider autistic people’s mental health and wellbeing, firstly ascertaining that the autistic population has significantly poorer mental health outcomes than the non-autistic population, and secondly considering what factors impact autistic people’s mental health. The next section of this chapter discusses both research areas.

2.2 Factors impacting the mental health of autistic adults

Until very recently, autism was considered a childhood disorder and so autistic adults were largely forgotten about in research (Kirby & McDonald, 2021). However, as the diagnosed adult population increases - due to diagnosed children reaching adulthood and the recent recognition of ‘lost generations’ of autistic adults not diagnosed until later in life - there has been a recent increase in research on the lives, priorities and needs of autistic adults (Kirby & McDonald, 2021), including the documented frequencies of co-occurring conditions, the types of healthcare received, and the costs of care (Benevides *et al*., 2020a). Along with a higher prevalence of many medical health conditions, quantitative studies have reported a significantly higher prevalence of mental health conditions (such as addiction, anxiety, bipolar, depression, eating disorders, obsessive compulsive disorder, schizophrenia, self-harm and suicidality) in the autistic adult population than in controls (Fombonne *et al*., 2020; Hand *et al*., 2020; Nimmo-Smith *et al*., 2019; Cassidy *et al*., 2018; Croen *et al.*, 2015).

A recent study found that 18.9% patients admitted to an adult psychiatric outpatient clinic met the criteria for autism, with a further 5-10% having subthreshold symptoms (Nyrenius *et al*., 2022). Meanwhile, mental health interventions for autistic adults do not appear to meet specific needs. Linden's *et al*. (2022) systematic review and network meta-analysis of randomised controlled trials looked at the benefits and harms of interventions to improve depression, anxiety and other mental health outcomes for autistic people. The authors concluded that of the 71 trials eligible for inclusion, a high risk of bias existed. As with Benevides & Cassidy's (2020) systematic review on interventions to address health outcomes for autistic adults, Linden *et al*. found that only cognitive behavioural approaches and mindfulness appeared to have evidence to support their use. Both studies highlighted a need for using outcome measures validated with autistic people, and avoiding outcomes that aim to reduce core features of autism.

In addition to the mental health conditions listed above, autistic burnout has been recently been defined as a distinct condition, described as "a syndrome conceptualized as resulting from chronic life stress and a mismatch of expectations and abilities without adequate supports. It is characterized by pervasive, long-term (typically 3+ months) exhaustion, loss of function, and reduced tolerance to stimulus." (Raymaker, 2020, p.140). A participatory study by Raymaker *et al*. (2020), using thematic analysis to analyse interviews and public internet sources, found that autistic burnout was distinct from clinical depression and occupational burnout. Autistic burnout is characterised by chronic exhaustion, loss of skills and reduced tolerance to stimulus. Participants described a depletion of physical, mental, emotional or social energy; a loss of skills necessary for daily living, socialising and regulating emotions; and an increased sensory intolerance, with even minor stimuli causing meltdowns and shutdowns. Similar findings on contributory factors to autistic burnout and autistic burnout characterisations are discussed in two other studies on autistic burnout, including a reflexive thematic analysis of public posts about autistic burnout carried out by Mantzalas *et al*. (2022a), and Higgins' *et al*. (2021) Grounded Delphi model of data analysis, which centred the participants as experts during three rounds of data collection combined with expert analysis to reach a community consensus of themes. As the concept of autistic burnout is still new to the literature, it is not currently included in prevalence studies, reviews, or intervention studies.

I now consider three main areas of factors impacting autistic adult's mental health. No previously established key groupings of factors existed that related to my area of research.

Following my review of the literature I identified three over-arching thematic areas. ‘Stigma, support and services’ covers the inaccessibility of support and services for autistic mental health needs; ‘Communication, camouflaging and compensating’ relates to how autistic people carry the burden of adapting their communication and behaviours to suit the needs of the non-autistic majority; and ‘Sensory environments, spontaneous interactions and social settings’ considers how social and sensory environments impact autistic people’s experiences of the social world.

Stigma, support and services

The burden of ‘acting normal’, the stigma of autism and mental health conditions, and barriers to support and services contribute towards mental health problems for autistic individuals (Mantzalas *et al*., 2022; Crane *et al*., 2019). Stigma is shown to have an association with lower levels of wellbeing and is associated with masking and compensating for social difficulties, and enabling autistic individuals to ‘pass’ as non-autistic (Perry *et al*., 2021). Botha and Frost (2020), who sought to understand whether stigma related stressors contribute to mental health problems in the autistic population, investigated the utility of the minority stress model originally designed for use with sexual and ethnic minority populations. Their quantitative findings suggest that stressors such as discrimination, expectation of rejection and internalised stigma are associated with poor mental health. As such, they consider that mental health problems such as anxiety, depression and suicidality should not be considered inherent to autism, but rather in response to societal attitudes to autism and autistic differences.

There are limited specialist mental health services for autistic individuals and many practitioners report lack of training, limited autism knowledge and low confidence treating autistic individuals (Maddox *et al*., 2019; Unigwe *et al*., 2017). Factors impacting healthcare interactions are divided between patient-level challenges and provider-level accessibility (Nicolaidis *et al*. 2015). At a user level, factors such as non-verbal communication, sensory sensitivities, fear, uncertainty, and challenges with organisation make accessing healthcare systems difficult for autistic people (Doherty *et al*., 2023; Strömberg *et al*., 2022; Raymaker *et al*., 2017; Dern & Sappock, 2016). Even when such systems are accessed, providers have a lack of autism knowledge, and are not always willing to provide alternative communication, accessible language, or other accommodations necessary to maintain patient autonomy and meet medical needs (Brice *et al*., 2021; Hallett & Crompton, 2018; Nicolaidis *et al*., 2015). Additionally, many autistic adults are dismissed for treatment because they are perceived as coping (Camm-Crosbie *et al*., 2019; Hallett & Crompton, 2018). One specific risk within medical and healthcare systems occurs when non-autistic practitioners expect autistic people to 'read between the lines', while those same practitioners simultaneously misread autistic patients' facial expressions and body language rather than listening to the actual words spoken (Strömberg *et al*., 2022). Next, I discuss this mismatch between communication styles.

Communication, camouflaging, and compensating

An autism diagnosis is dependent on "*evidence of persistent deficits in social communication and social interaction*" (American Psychiatric Association, 2013). However, Damian Milton's Double Empathy Problem (DEP) describes how the fault in conveying meaning is not located in the autistic person, but rather in the different contextual understandings between autistic and non-autistic people (Milton, 2012a; Milton *et al*., 2022). Research by Crompton *et al*. (2020b) supports this theory, finding that information transfer between pairs of autistic participants is as effective as between pairs of participants who are not autistic, but that mixed pairs are significantly less effective. In conversational interactions between autistic, non-autistic and mixed pairings, participants prefer partnering with their own neurotype, and disclose more information, suggesting that social interaction difficulties are relational, rather than an individual impairment (Morrison *et al*., 2020).

The implication of how the DEP might affect the mental health of autistic people is explored by Mitchell *et al*. (2021), who consider that being misunderstood or misperceived by others might create a barrier to social experiences. Such research contrasts with a general assumption that autistic people are not socially motivated (e.g. Chevallier *et al*., 2012), which has been contradicted by research studies seeking autistic people's views on the matter (Quadt *et al*., 2021; Pellicano *et al*. 2019; Jaswal & Akhtar 2018). Rather, autistic people describe how belonging to social groups contributes to improved wellbeing (see Maitland *et al*., 2021; Crompton *et al*., 2020a; Lam *et al*., 2020), and how loneliness can lead to extreme distress (Quadt *et al*., 2021). However, the cost of social interactions when the onus is placed on the autistic person to adapt their communication style can be high, and understanding autistic forms of communication is vital in developing non-pathological understandings of autistic social interaction (Cook *et al.*, 2023; Davis & Crompton, 2021; Cummins *et al.*, 2020). For instance, not all autistic people use speech to communicate, and those who do may experience intermittent, unreliable and/or insufficient speech[7] (Zisk & Dalton, 2019), particularly when an environment or situation (such as accessing services) is experienced as overwhelming (Cummins *et al.*, 2020; Howard & Sedgewick, 2021).

As well as shouldering the burden to adapt communication when interacting with non-autistic people (as already described), autistic adults also report learning to camouflage or mask in order to fit in and avoid stigma. While camouflaging is not limited to autistic individuals, some aspects appear to be specific to the autistic experience (Miller *et al.*, 2021). Autistic camouflaging can be considered as a range of masking and compensating techniques used to disguise an individual's neurodivergent differences and may include: minimising stimming, performing a role (modelled on known individuals or fictional characters), maintaining eye-contact, displaying expected facial expressions or body language, making small talk, restricting talk about intense interests, and scripting conversations (Hull *et al.*, 2017). Meanwhile, Lawson (2020) discusses how the terms 'camouflaging,' usually used in academic literature, and 'masking,' more commonly used in the autistic community, suggest the intention and ability to deliberately conceal one's autistic identity, and proposes the term 'adaptive morphing' to describe what seems more likely to be an unintentional survival strategy.

The suppression of natural autistic social responses may be a response to the deficit narrative of autism and its accompanying stigma, a direct result of behavioural interventions, a lack of safe spaces to exhibit one's full identity, and/or a response to high levels of social anxiety (Pearson & Rose, 2020; Cage & Troxell-Whitman, 2019). Many autistic people feel that camouflaging is necessary to connect socially, maintain relationships, obtain jobs and qualifications, be valued and reduce the chances of being bullied (Bradley *et al.*, 2021; Cook *et al.*, 2021; Hull *et al.*, 2017). However, higher levels of camouflaging are associated with higher anxiety symptoms, depression, suicidality, social

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[7] Zisk and Dalton (2019) describe intermittent speech as not always being able to speak; unreliable speech as saying things that do not match the intended meaning; and insufficient speech as not fully meeting communication needs.

anxiety and autistic burnout (such as Hull *et al*., 2021; Raymaker *et al*., 2020; Cage & Troxell-Whitman, 2019, Cage *et al*., 2017; Cassidy *et al*., 2018).

Regardless of terminology, intent or potential payoffs, masking contributes towards individuals feeling exhausted, anxious and feeling unsure of who they really are; experiencing feelings of inadequacy and shame; and those around them not believing that they are autistic or in need of supports (Harmens *et al*., 2022; Bradley *et al*., 2021; Cook *et al*., 2021; Crompton *et al*., 2020a). In contrast, when autistic people feel empowered to socialise in a more autistic interpersonal style - engaging in more autistic body movements, levels of reciprocation and conversational exchanges - feelings of ease, authenticity and enjoyment are experienced (Cook *et al*., 2023; Black *et al*., 2023; Cook *et al*., 2021). Mandy (2019) highlights how camouflaging demonstrates an adaptive, resourceful response to operating in social environments shaped by non-autistic people, but also draws a link between autism interventions that place the onus on the autistic children to think or act differently to fit in with normative social conventions, and poor mental health experiences for autistic adults who make those same social changes.

Sensory environments, spontaneous interactions and social settings

Sensory sensitivities are a particular and complex problem for many autistic adults (World Health Organisation, 2018). Sibeoni's *et al*. (2022) metasynthesis of qualitative studies describing sensory issues reported by autistic people (32 studies, 430 participants) identified four dimensions: physical, emotional, relational and social; and the results suggest that these dimensions are experienced holistically, as inseparable, and not hierarchically or in terms of cause and effect. Hyper- or hypo-reactivities to sensory input can cause significant stress and feeling of exhaustion for autistic people in their daily life (Millington & Simmons, 2023; Parmar *et al*., 2021; Bogdashina, 2016; Milton, 2012). Individuals may experience hyper-reactivities to a range of stimuli including loud or high-pitched noises, bright or flickering lights, sour tastes, labels or seams in clothes, environmental heat/cold, and the body smells of other people (Strömberg *et al*., 2022; MacLennan *et al*., 2021a; Milton, 2012). Hypo-reactivities may include being unaware of extreme temperatures, being thirsty, needing the toilet or experiencing pain (MacLennan *et al*., 2021; Milton, 2012). Meanwhile, many autistic people are sensory-seeking, requiring experiences such as music, deep pressure, visual patterns, certain smells and textures to feel regulated (MacLennan *et al*., 2021; Bogdashina, 2016). While mental-health challenges related to sensory sensitivities have been known outside of academia for some time, hyper- and hypo-sensory sensitivities were first shown in a recent online study with autistic adults (*n*=246) as having a significant correlation with anxiety; with hyper-sensory reactivity differences appearing to cause increased anxiety, and sensory-seeking differences appearing to be an effect of anxiety (Verhulst *et al*., 2022).

Additionally, individuals may have more complex sensitivities such as aversions to certain types of touch, misphonia (when everyday sounds such as chewing or whispering trigger extreme emotional or physiological responses), being unable to filter concurrent conversations, and synaesthesia (the joining or merging of sensations from a single sensory input, such as when hearing colours or tasting sounds), all of which may cause problems with mental focus and physical balance (Elwin *et al*., 2013). Certain sensory inputs, and particularly multiple inputs, can cause fear and anger, and a strong desire for attacking the source(s) or escaping the situation (MacLennan *et al*., 2021; Bogdashina, 2016; Smith & Sharp, 2013). Fatigue, stress and an impact on day-to-day activities arise from visual stressors, including light, motion, patterns and particular colours (Buckle *et al*., 2021; MacLennan *et al*., 2021; Parmar *et al*., 2021; Livingston *et al*., 2019). Often the sensitivities that distress autistic people are related to the people around them (Stromberg *et al*., 2022; Parmar *et al*. 2021; Sinclair, 2010) and as a result, many autistic people avoid social situations due to social environments often involving overwhelming background noises, visual distractions and multiple concurrent conversations (Black *et al*., 2023; Parmar *et al*., 2021; Landon *et al*. 2016).

Together with sensory sensitivities, an intolerance of uncertainty - the tendency to react negatively to unforeseen or unpredictable events - has been found to have a positive correlation with anxiety for autistic individuals (Stark *et al*., 2021; Hwang *et al*., 2020; Cai *et al*., 2018). Unexpected sensory stimuli can be particularly distressing and disabling (MacLennan *et al*., 2022a; MacLennan *et al*., 2022b). However, it is uncertain whether anxiety caused by uncertainty increases sensory sensitivities for autistic individuals, or whether anxiety caused by sensory sensitivities causes additional intolerance of uncertainty (Neil *et al*., 2016).

Autistic people often differ from people who are not autistic in social interactions as well. Autistic social communication is less likely to begin with small talk, and is more likely to centre around a subject of intense interest (Cummins *et al*., 2020; Hickey *et al*., 2018; Milton & Sims, 2016; Sinclair, 2010). Group situations involving multiple social cues and unstructured social settings are more demanding on compensatory resources for autistic people (Livingston *et al*., 2019). Such differences in how autistic people experience social settings contribute to being less likely to access social events, which may contribute towards feelings of loneliness. A systematic review of studies on loneliness in autistic adults (Umagami *et al*., 2022) highlighted autistic adults' desire to socially connect with others; all studies comparing autistic and non-autistic adults found higher levels of loneliness in the autistic groups. Factors positively associated with social isolation or loneliness included a lack of autism understanding and acceptance by others, sensory avoidance and camouflaging, each of which have been included in this chapter section.

So far, this chapter has discussed how outsider, medical and/or pathologising understandings of autism and autistic people are slowly ceding to insider, social and neutral understandings. Viewing autism as a collection of deficits has been highly damaging to the mental health and wellbeing of autistic people as they navigate systems which ask them to overcome specific sensory challenges and stigma while behaving and communicating in a way deemed socially acceptable by non-autistic society. This navigating of non-autistic systems has implications for a potential autistic need for time alone, or at least time away from the systems that negatively impact mental health and wellbeing. The remainder of this review will focus on how emancipatory research is leading the way in advocating for autistic people to live more authentically, find their place in society, and improve their mental health and wellbeing.

2.3 What an emancipatory approach brings to autism knowledge

Since Kanner and Asperger, many individuals and schools of thought have claimed autism expertise, and yet autistic voices have traditionally been silenced (Milton, 2014; Milton & Bracher, 2013). In contrast, emancipatory research assumes that there are multiple realities, recognises power imbalances in research, acknowledges that knowledge is not only created by the dominant group, and seeks to empower the subjects of social enquiry (Aidley &

Fearon, 2021; Noel, 2016; Jupp, 2006). Stone and Priestly (1996) identify six principles of emancipatory research in relation to disability: (1) the research agenda should be based on a social theory of disability, (2) there must be a commitment to disabled people's self-empowerment, (3) research should contribute towards the removal of disabling barriers, (4) research should be accountable to disabled people and their organisations, (5) individual and shared experiences should be heard, and (6) the needs of disabled people should determine the research methods.

Emancipatory autism research, which may focus on critical perspectives and/or use participatory approaches (Noel, 2016; Reason & Bradbury, 2013), challenges predominant, deficit-based constructions of autism, and takes autistic narratives and cultural expressions into account (Woods *et al.,* 2018; O'Dell *et al*., 2016). Chown *et al*. (2017) view all emancipatory research as participatory in nature and so, for clarification, the next few paragraphs first explore the emerging field of Critical Autism Studies (CAS), and are followed by an outline of the nature of community based participatory autism research.

Critical Autism Studies and philosophical assumptions

While few autism researchers explicitly state their own philosophical assumptions, the epistemological views and theoretical models underpinning research create divisions in the production of autism knowledge. For instance, autism definitions in the academic literature commonly reference deficit-based frameworks and models, such as those discussed earlier in this chapter, including the 'triad of impairments' in communication, social interaction and social imagination, the ToM model, and the Systemising/Empathising quotient. These models do not stand up to philosophical scrutiny because the underlying structures and mechanisms are based only on observations of behaviour in a narrow range of autistic people (Kourti, 2021); however, their legacies continue to inform contemporary research and praxis. Meanwhile, research priorities have almost exclusively been set by scientific funders and academics without involving autistic people in the decision-making processes (Pellicano *et al*., 2019) leading to stark contrasts between funding patterns and community priorities (Benevides & Cassidy, 2020; Pellicano et al., 2014).

A positivist reliance on deficit-based autism theories creates epistemic disablement for autistic people, through ignoring their accounts of experiences and needs (Catala *et al*., 2021). Further, the ToM model, which suggests that autistic people cannot understand their own mental or emotional states as separate from other people's, creates a Catch-22 situation for the concept of autistic agency. Yergeau describes this situation: "*1. They [clinicians] can argue that autistic people are not autistic enough to make claims about autism. 2. They can likewise argue that autistic people are too autistic to make claims about autism*." (2018, p.50).

In contrast, emancipatory research approaches such as CAS, as with Critical Disability Studies and Critical Race Studies, focus on assessing and critiquing society and culture to reveal and challenge power structures. While these approaches are not necessarily tied to any particular philosophical perspectives, research worldviews such as constructivism, pragmatism and critical realism lend themselves to recognising and resisting autistic disability through a social disability lens, i.e. understanding autistic disability as resulting largely from societal barriers (Chown *et al*., 2017). Emancipatory autism research challenges clinical and mainstream perceptions of autistic people 'suffering from autistic spectrum disorder,' through (1) describing the extrinsic – and thus, not inherent - causes of distress and mental ill-health, and (2) describing the capacity for autistic people to thrive in appropriate social and sensory environments. Ryan and Milton (2023) argue that CAS highlights how recognising and acting on the "*constraints of social environment, structures and cultures*" (p. 3) is essential to generate change which improves the wellbeing of autistic people.

CAS builds on autistic scholarship to investigate power dynamics within autism discourses (Woods *et al*., 2018). It has a particular role to play in correcting historical and current epistemic injustice, through which autistic individuals are not understood to have epistemic agency - the capacity to produce, transmit and use knowledge about themselves - causing a divide between first- and third-person accounts of the nature and experience of autism (Catala *et al*., 2021). Without accounting for autistic people's epistemic agency, autism researchers fail to appreciate that autistic people experience the world differently, perhaps ironic given that so much credence is given to the autistic lack of ToM. For example, interventions aimed to reduce autistic meltdowns[8] are often based on the long-held belief that the observed meltdown behaviours are temper-tantrums (e.g. Nuta *et al*., 2021; Ahemaitijiang *et al*., 2020; Singh *et al*., 2019) while community autism knowledge, gained from both autistic experience and interaction with other autistic people, leads to understanding that meltdowns frequently result from overwhelm (Kourti, 2021). In practice this means that well-intentioned interventions aiming to treat ‘aggressive’ or ‘tantrum’ behaviours, and which stem from philosophical claims to objectivity and infallibility in autism research, are thus absolved from addressing environments that cause overwhelming distress.

Of the emancipatory autism researchers who state or describe their theoretical frameworks, most appear to take either constructivist or critical realism perspectives. Autistic researcher Chapman (2020a) argues for a constructivist perspective in autism research, one which dismisses reducing autism to any specific genetic, neurological or psychological traits in favour of exploring autistic people’s shared relationship to external factors such as sensory barriers and structures of working and learning environments. Other autistic autism researchers argue for a critical realist approach which recognises that while the intersection between neurotype and social environment, or biology and culture is complex and subjective, it has a measurable impact on those studied (Miller *et al*., 2021; Botha, 2021a; Kourti, 2021). Critical realism is also considered to lend itself well to an interdisciplinary approach, which offers value to autism wellbeing research through blending multiple fields, including biology, psychology, sociology and social care (Botha, 2021a; Bhaskar *et al*., 2018). Further, a framework such as critical realism suggests that as the absence of ‘biological markers’ (clear biological explanations for autism) leaves the diagnostic category of autism to be based on observed behaviours; the label ‘autism’ should thus should be considered a ‘fictitious placeholder’ (Bhaskar *et al.*, 2018). Similarly, critical realist researcher Botha (2021a) notes that the very meaning of autism is tied to time, place and culture.

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[8] Autistic meltdowns are intense, involuntary and highly distressed responses to an overload of information. They may manifest verbally (crying, shouting, screaming etc.) or physically (including punching or kicking objects, oneself or other people).

Participatory autism studies

If autistic people are not actively involved in the process of knowledge production, then their epistemic contributions are disregarded, leaving understandings of autistic wellbeing to be framed only by third-person observers (Pellicano & Heyworth, 2023; Catala *et al*., 2021; Milton & Bracher, 2013). Historically, this has resulted in intervention success being measured in the reduction of autistic characteristics (arguably a form of sanctioned camouflaging) rather than asking participants if their lives have been improved (Mueller, 2020). Freezing autistic people out of processes of knowledge production has created a mistrust of research (Milton, 2014) but, in contrast, Community Based Participatory Research (CBPR) is an emancipatory approach using scientific rigour to disrupt the ways that science contributes to institutionalised oppression (Raymaker, 2020).

Participatory approaches in autism research can take a number of forms, from CBPR projects to collaboration with autistic academics. In the past decade, several participatory partnerships have contributed to good-practice recommendations in autism research, including the Participatory Autism Research Collective (PARC), and the Academic Autism Spectrum Partnership in Research and Education (AASPIRE). Large-scale participatory projects in the UK, Australia and Canada have further identified ways in which participatory research with autistic people can become welcoming, effective, respectful and inclusive through shaping supportive research environments, paying attention to methodological challenges for those with additional accessibility needs, and ensuring that autistic partners do not experience a lack of power and control (Fletcher-Watson *et al*., 2019; den Houting *et al*., 2020; Jose *et al*., 2020). Further, CBPR projects reflect a recent interest in how the mental health of autistic adults might be improved or maintained. Research priorities identified by CBPR projects include trauma-informed care approaches, inclusion and acceptance of autistic individuals, community-available approaches for self-management of mental health, evaluation of adverse mental health outcomes of existing interventions, and improvements in measuring quality of life and social wellbeing (Benevides *et al*., 2020b).

Research incorporating CAS positioning and CBPR methods makes a clear argument for meaningful involvement from autistic people, not just at multiple stages of research projects, but also in the conceptualisation of autism itself. An emancipatory approach is vital in centring autistic experiences in autistic mental health and wellbeing research; without this, it would be difficult to understand why autistic people have poorer mental health and wellbeing, and thus how autistic mental health and wellbeing might be improved. The final section of this review will discuss research which has been largely emancipatory and which focuses on how autistic people manage their own mental health.

2.4 Existing research on autistic wellbeing

This final section is largely concerned with how autistic people improve their own mental health and wellbeing through embracing autonomous and authentically autistic ways of living, and using self-managed wellbeing strategies including engaging in intense interests, self-regulating using repetitive physical movements, and creating ‘autistic-friendly’ social and sensory environments. Many of these ways of living and wellbeing strategies reframe elements of the autism diagnostic criteria, strengthening the argument that observable autism ‘deficit traits’ may be better understood as value-neutral differences in how autistic people interact with the world.

Self-acceptance, social interaction, autonomy, self-advocacy and coping mechanisms

Autistic adults often find that after their diagnosis or identification[9] of being autistic, they go through a period of adjustment including grief and/or anger for the lack of understanding they had experienced from others and themselves prior to this time (Harmens *et al*., 2022; Corden *et al*., 2021; Leedham *et al*., 2019; Stagg & Belcher, 2019, Hickey *et al*., 2018). Following this, a sense of a new and positive identity may emerge for that individual, together with discovering a new community, letting go of self-blame, being more self-assertive and giving themselves permission to meet their own needs (such as Harmens *et al*., 2022; Lilley *et al*., 2021; Corden *et al*., 2021; Cooper *et al*., 2021; Leedham *et al*., 2019).

The diagnostic criteria reference persistent deficits in social communication and social interaction and, in particular, deficits in developing, maintaining and understanding relationships (American Psychiatric Association, 2013). As such it is often assumed that

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[9] Autistic adults who (1) do not yet have a clinical diagnosis of autism, (2) have chosen not to pursue a diagnosis, or (3) choose not to engage with the medical terminology of an autism diagnosis may refer to identifying as autistic, or being identified (by another) as being autistic.

autistic people do not want relationships and social interactions. As outlined earlier in this chapter, factors such as stigma, sensory environments, and communication differences between autistic and non-autistic people make many social settings less welcoming and accessible for autistic people, often leading to loneliness and isolation. The increase of global neurodivergent online communities reflects many autistic people's desire and need for social communication and interaction. Autistic participants in Crompton's *et al*. study (2020a) reported that socialising with other autistic people was more comfortable and less tiring than with non-autistic people: they felt less need to mask, communication was easier, social activities were more likely to be mutually enjoyable and they had more shared understandings. Similar findings were reported in Howard and Sedgewick's (2022) research on communication preferences for autistic people. Socially identifying with the autism community is associated with less severe depression symptoms, develops a positive sense of identity, strengthens social connections and raises feelings of collective self-esteem (Cooper *et al*., 2021; 2017; Maitland *et al*., 2021).

Through communicating with other autistic adults, particularly online, many late diagnosed autistic people develop new understandings about what they need for their own wellbeing (Mantzalas *et al*., 2021; Hickey *et al*., 2018). Being able to self-advocate for necessary accommodations and develop appropriate coping mechanisms is important for reducing overwhelm, anxiety, and crisis situations but these tools are not always apparent to those who have yet to discover their autistic identity, or autistic community (Lilley *et al*., 2021; Leedham *et al*., 2019; Hickey *et al*. 2018). Online communities, such as those forged through social media, can help autistic people to develop and share non-pathologised understandings of what it means to be autistic, particularly in the absence of positive representations in the media (Egner, 2022). Support is rarely available, even for adults with a clinical diagnosis of autism, and so experience-led practical coping strategies offered by peers can lead to feelings of empowerment (Crane *et al*., 2021). Late diagnosed adults often find that after their diagnosis or identification they feel empowered to ask for accommodations to be made, which previously they were unaware they could ask for (Corden *et al.* 2021; Webster & Garvis, 2017).

Monotropism and flow state

While the majority of psychological models of autism are based on interpretations of observed behavioural traits (Milton, 2012), the theory of Monotropism, as proposed by autistic scholars Dinah Murray and Wenn Lawson (2005), is based in subjective accounts of how autism is experienced. Monotropism considers that all individuals have a limited amount of attention available at any given time, but that where most people have a polytropic tendency, with attention broadly distributed over many interests, autistic people's focus is narrow and tightly focussed. Murray *et al.*'s original theoretical paper on Monotropism (2005) explains in detail the diagnostic criteria in relation to a tendency for hyper awareness within an 'attention tunnel'. When an autistic individual is integrating multiple sources of sensory input, the myriad of rules involved with social interaction and communication fight for attention; causing difficulties with cognitive attention shifting. When that individual is then faced with unanticipated change or a failure to meet expectations, the ultimate result may be *"a complete disconnection from a previous safe state, a plunge into a meaningless blizzard of sensations, a frightening experience which may occur many times in a single day."* (p.147).

Monotropism may therefore offer an alternative to Kanner's original description of autism as a disorder "*characterized by extreme aloneness and preoccupation with the preservation of sameness"* (Eisenberg & Kanner, 1956, p.565). In the context of Monotropism, avoiding social environments and trying to maintain 'sameness' would not therefore be considered a disorder, but rather as a way of reducing sensory, social and cognitive overwhelm. Monotropism explains how complete absorption in an activity or sensory experience can sometimes be problematic in social situations or if the individual finds themselves unable to break out to rest or do another activity (Buckle *et al.*, 2021; MacLennan *et al.*, 2021a; Murray, 2021). It also explains the hyper-focusing abilities of many autistic people, which may contribute towards recognised success in fields where autistic individuals have a particular interest (South & Sunderland, 2020).

One little researched area of autistic wellbeing centres around the need to access 'flow state', a term coined and described by Csikszentmihalyi as "*a state in which people are so involved in an activity that nothing else seems to matter*" (1990, p.15). In positive psychology this immersion in an activity or 'hyperfocus' is seen as a positive state, particularly in the creative arts, sports or the workplace. However, in medical-model autism discourses this immersion is often described in terms such as ‘restrictive’, ‘fixated’, ‘circumscribed’, and ‘perseverative.’ Ashinoff and Abu-Akel’s review of how hyperfocus is defined and measured in academic literature, particularly with reference to autism, ADHD and schizophrenia, neglects to refer to Monotropism and instead relate hyperfocus to the deficit-led diagnostic criteria to conclude that, “*it is unclear if hyperfocus is a primary symptom or a secondary symptom that is merely induced by other ASD related behaviors*” (2019, p.12). However, engaging in ‘special interests’, ‘intense interests’, or even “*highly restricted, fixated interests that are abnormal in intensity or focus*” (American Psychiatric Association, 2013) may have a positive impact on autistic wellbeing (Lam *et al*., 2020; Wood, 2021; Grove *et al*., 2018; Koenig *et al*., 2017; McDonnell & Milton, 2014). The flow-like states bought about by engaging with areas of intense interest can be seen as a necessary coping strategy (Hickey *et al*., 2018; McDonnell & Milton, 2014). Intrinsic motivation, described by Deci & Ryan (2000) as motivation represented by autonomous behaviour regulation resulting in pleasure or satisfaction, appears to be a more important driver towards engaging with interests for autistic adults, than for non-autistic adults (Murray, 2020; Grove, 2018).

A need for understanding and supporting a monotropic tendency is clear in autistic adults’ accounts within qualitative studies, and with clear benefits to wellbeing. Sensory stimuli and social environments compete for attention and so channelling a flow state becomes more difficult in certain environments (Murray, 2021). Autistic people talk about how time alone gives people the opportunity for uninterrupted pursuit of interests (Hickey et al. 2018), and how withdrawing with projects to recover and replenish energy helps avoid autistic burnout (Higgins *et al*., 2021; Milton & Sims, 2016). Having a sense of structure and routine enables autistic people to maintain a naturally narrow focus, without the distraction of adapting to change and uncertainty; and controlled or predictable input makes it easier to filter, to focus or to deal with feelings of overwhelm (Murray, 2008; Milton & Sims, 2016). A Monotropism self-report measure is currently in development, with early validation studies suggesting that both autistic and ADHD status is associated with higher mean monotropic scores (Garau *et al*., 2023).

Sensory regulation and stimming

‘Self-stimulatory’ behaviour, also known clinically as stereotypy but colloquially referred to as *stimming*, is included in the DSM-5 as: “*Stereotyped or repetitive motor movements, use of objects, or speech (e.g. simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).”* (American Psychiatric Association, 2013). Numerous behavioural interventions seek to reduce these movements, ostensibly to improve ‘normal functioning’ (Patriquin *et al*., 2020). However, autistic people maintain that stimming can be soothing, relaxing, invigorating and/or enjoyable; a way to distract from physical, mental or emotional discomfort; a way to enhance positive feelings such as calmness and joy; or even as “*an improvisatory practice [which] drives embodied cultural expressions highlighting autistic aesthetics and sensory preferences*” (Felepchuck, 2021, p.1). While non-autistic people also stim (for instance hair twirling, nail biting, and finger tapping), it is significantly more common in autistic people (Charlton *et al*. 2021). In the first empirical study on positive aspects of stimming, Kapp’s *et al*., (2019) autistic participants described how stimming helped regulate (1) overwhelming environments, (2) sensory overload, (3) noisy thoughts and (4) uncontainable emotion. Similarly, Charlton’s *et al*. (2021) survey of adults who stim, found that stimming was felt to reduce symptoms of sensory overload (including headaches, vomiting, disorientation, anxiety and/or confusion), and regulate emotional and cognitive functioning. Societal pressure to supress stimming, or to substitute obvious stims with subtler stims, causes additional distress and an increase of symptoms relating to sensory overwhelm (Collis, *et al*., 2022; Charlton *et al*., 2021; Mantzalas *et al*., 2021; Kapp *et al*., 2019). Conversely, being able to stim around other people has been identified as one of the ways that autistic people feel that they can be their ‘authentic selves,’ enabling relaxation with friends and family and fostering a sense of community with other autistic people (Crompton *et al*., 2020a).

Autistic spaces

Felepchuck (2021) describes spaces designed for people without sensory processing differences as “*inaccessible sensory landscapes*” and yet research within the dominant pathology paradigm contributes to interventions aiming to reduce the individual’s behavioural response to uncomfortable sensory experiences rather changing or adapting the environments themselves. In environments designed by educators and service providers, particularly places where autistic people may be kept involuntarily, autistic processing and functioning is often undermined (Sinclair, 2010). Anecdotal evidence demonstrates that autistic people placed in seclusion in Assessment and Treatment Units for challenging behaviours such as aggression and self-harming experience a sharp decrease in mental health (*"File on 4"*, 2021; Baggs, 2020; Quinn, 2018). This is a far cry from the refuge of one's own home or room, described by Sinclair (2010) as a place where autistic people have control over the space itself. The National Development Team for Inclusion's reports, on supporting autistic people at home and in inpatient settings, focus on adapting sensory environments for the best outcomes (NDTi, 2020a; NDTi, 2020b). These reports, co-produced with autistic people, view autism as a sensory difference and use Beardon's principle "Autism + Environment = Outcome" to explain how the environment can either support an autistic person or push them into a sensory crisis situation (Beardon, 2017, p.11).

Research into the types of sensory environments preferred by autistic people is limited. But practical measures to improve shared areas by reducing sensory challenges encourage autistic people's feelings of being calm, focussed and engaged (Doherty *et al*., 2023; Martin *et al*. 2019; Brand & Gaudion, 2012). Such measures may include reducing visual displays, odours and distracting noises; and encouraging the use of sensory tools such as tinted glasses and noise-reducing headphones (Black *et al*., 2022; Buckle, 2020; Lowe *et al*., 2014; Brand & Gaudion, 2012; Sinclair, 2010). Meanwhile, autistic community spaces which accept and encourage autistic ways of being, thinking and moving allow autistic people to be their authentic selves and thus improve their wellbeing (Farahar, 2023). Those who have experienced autistic spaces report "*mutual acceptance and empathy with others, feeling less isolated, building friendships, meeting new people, having control over the 'discourse', enjoyment of leisure activities, acceptance of difference, interaction aides, commonality and 'love'*" (Milton & Sims, 2016, p.529).

Conclusions and rationale for current study in literature

This literature review has discussed some of the key aetiological understandings of autism, and considered how these understandings might differ in how they (1) inform conceptualisations of good autistic mental health, (2) explain barriers to good autistic mental health and (3) identify factors that improve autistic mental health and wellbeing.

The review was in four parts, outlining: (1) a historical overview of autism research from pathological beginnings to newer social disability perspectives, (2) factors influencing poor autistic mental health, (3) emancipatory autism research, and (4) factors influencing improved autistic mental health and wellbeing. This overview has traced a path from how the link between autism and poor mental health has been largely understood as intrinsic to the autism within the person, to how researchers are increasingly exploring extrinsic factors such as sensory environments, stigma, and services that do not take autistic social and sensory processing into account. However, it is important to clarify that this shift has not universally taken place in all autism research communities; here I have only traced the chronological path that has informed my own research.

In Chapter One I discussed how autistic wellbeing has been neglected in the literature due to a lack of consensus concerning whether autistic people can experience wellbeing, the epistemic validity of autistic people's individual and community knowledge, and whether autistic people's wellbeing goals should reflect those of the wider population or reflect different priorities. The profound shift in understanding that, for autistic people, mental health improvements can be made from changing social and sensory environments rather than the individual, also has implications for wellbeing, which I introduced in Chapter One as a flexible state of feeling good and functioning well cognitively, emotionally, and socially. Although autistic wellbeing is frequently discussed on social media, there is very little in the literature to reflect that autistic people do not just want themselves and their communities to not experience poor mental health, they want community input into the concept of what it might mean to thrive as an autistic person, and research that reflects autistic people's preferred routes to wellbeing.

The next four chapters outline my PhD research methodology, and present and discuss my findings for the mixed-methods study I undertook to explore how alone-time impacts autistic people's wellbeing. My integrated findings (Chapter Six) contribute towards understanding the role of alone-time in preferred environments as an autonomous wellbeing strategy to improving and maintaining wellbeing for autistic adults.

Chapter Three: Methodology Part 1

> "Anyone who writes about autism or autistic people should be engaging reflexively with their presuppositions, their values, and positions and would do well to remember that there will always be an autistic person who reads it."
>
> - *Monique Botha (2021), autistic researcher (via twitter).*

As discussed in the previous two chapters, autistic wellbeing is a new area of research. Historically it was assumed that (1) autistic people were not able experience wellbeing, (2) that it was not relevant to seek autistic people's views concerning what wellbeing meant to them, and (3) it was not relevant to seek autistic people's views concerning what factors they felt impacted their own wellbeing. Research into autistic wellbeing therefore necessitates putting aside theories and concepts reliant on the positivistic and pathologised autism research which dominates autism literature. Rather, autistic wellbeing literature reflects how the field has, over the past two decades, been slowly built from the ground up, developing theories which rely on autistic understandings based on lived experience. The methodological considerations for my PhD research were thus embedded within this emancipatory field; I intended to centre autistic people's views concerning their own wellbeing, through the design, development and delivery of my research.

This methodology chapter, the first of two, is divided into four distinct sections. The first is concerned with my PhD study as a whole; it presents my positionality as an autistic autism researcher, and describes the pragmatic approach that I took in framing my research. The second section outlines the study design, and introduces the inclusion of a community advisory group for this study. The third section of this chapter is concerned with describing the methodological considerations for collecting qualitative data, including the ethical considerations, data collection, and the interview procedure. In the fourth and final section I detail my approach to analysing the qualitative data. The development and analysis of the quantitative phase, and the integration of the two phases are discussed in Chapter Five.

3.1 Positionality and pragmaticism

As I describe later in this chapter section, my research methods and research design utilised a pragmatic approach. However, my personal philosophical position could be loosely interpreted as critical realist; while I believe that autism can, and should be considered ‘real’, I consider that social contexts and meanings shape definitions and understandings of what autism is and how it can be understood. As discussed in the previous chapter, many neurodiversity-led academics approach autism research from a critical realist perspective as they consider that the autistic experience is tangibly different from the non-autistic experience, while acknowledging that intersectional identities (including gender, ethnicity, disability and socio-economic background) have a marked impact on an individual's autistic experience; thus the ‘autistic experience’ is not universal. Although various pragmatist and critical realist theorists differ in how they approach realist and relativist ontologies, taking a pragmatic approach while holding a critical realist position is not incompatible as both frameworks allow that ‘knowledge’ is not necessarily the same as ‘truth’ (Elder-Vass, 2022). While my research is informed by current, neurodiversity-led, accepted knowledge about autism, I appreciate that this knowledge may not hold true in the future. I explore the importance of holding this viewpoint - that currently accepted knowledge concerning the nature of autism may well change in the future - in the final chapter of this thesis.

My research aimed to answer three research questions

RQ1: To what extent do autistic adults choose to create regular time alone?

RQ2: How and where do they choose to spend this time?

RQ3: Is there an association between using this time and space, and self-reported levels of wellbeing?

Arguably, these questions might be answered differently by a researcher who was not autistic, or who had chosen a different theoretical framework; and so some explanation of my positionality - the social context which shaped and influenced how I understand my own research aims and why I chose the methods that I did - seems an appropriate place to begin this chapter.

Positionality: an autistic autism researcher

The current study was identified as an underexplored area of the literature by myself, a woman who was not identified as autistic until my forties. Through my own life experiences, my 2019 MRes research project with other late-diagnosed autistic women, discussions with other autistic people, and reading non-academic writing by other autistic people, it was apparent to me that many autistic people view regular time in solitude within chosen sensory environments as highly necessary for their wellbeing. This need for time alone is not currently discussed in depth in the literature, although related elements such as autistic masking, sensory sensitivities and flow-state have been researched in some detail (see Chapter Two). While planning and carrying out the literature review, data collection and analysis I worked from an ontologically emic position: recognising that autistic communication and behaviours are meaningful to autistic culture, and operate from a context of autistic experience (Holmes, 2020).

Within this research area I also have an insider perspective; considering myself a member of global autistic and autism communities[10]. Advantages from having an insider perspective into autism research include

1. having epistemic privilege, experiential knowledge of autistic culture, experience and communication styles (Pellicano *et al.*, 2022b; Dwyer *et al.*, 2021; Holmes, 2020)
2. not being held back, as non-autistic autism researchers may be, by Milton's Double Empathy Problem[11] (Milton, 2012)
3. having a vested interest in domains and frameworks identified as important to the autistic community but so far neglected by academia (Dwyer *et al*. 2021; Holmes, 2020)

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[10] The *autistic community* comprises multiple communities (often online) predominantly of autistic adults and young people. The *autism community* comprises multiple communities (also, often online) of parents and carers of autistic children or adults cared for at home, clinicians, autism practitioners and autistic people. The histories, goals and motivations of the autistic and autism communities are not always aligned (Botha & Gillespie-Lynch, 2022).

[11] Milton's Double Empathy Problem (DEP), as discussed in the literature review, suggests that empathy is a two-way process that depends on expectations from previous social experiences. As social experiences are different for autistic and non-autistic people, the DEP describes the resulting breakdown in communication.

4. likely being regarded by participants as more trustworthy than if I was a non-autistic researcher, and as treating their insights and experiences with more respect (Dwyer *et al*., 2021; Pellicano *et al*., 2022)
5. likely easier access to participants from the culture being studied (Holmes, 2020).

Additionally, interviews where both the participants and interviewer are autistic reduces many communication difficulties inherent in cross-neurotype[12] interviews, with the participant feeling less pressure to make eye-contact, 'perform' emotions or modulate behaviours and/or vocal tone (Howard & Sedgewick, 2021).

Autistic scholar Milton states that social research in autism must involve autistic scholars to claim ethical and epistemological integrity (2014). However, this can come at personal cost to the researcher, through balancing a line between professional and personal engagement with the researcher's own community under research, and through engaging with research with opposing epistemological frameworks. Autistic researcher Raymaker reflects that being an insider researcher in a community-based participatory research setting means that the intersection with her professional and scientific roles can make her suspect to her autistic community (2016). Meanwhile autistic researchers, such as Botha and Yergeau, describe how distressing it is to engage with dehumanising autism research which denies that autistic people have Theory-of-Mind or empathy, describes autism in terms of aggression and immorality, and questions the necessity of agency or autonomy for autistic people (Botha, 2021b; Yergeau 2018).

My approach to this PhD research was clearly not objective; my own need for, and interest in the little-explored concept of time alone for autistic wellbeing means that not only was I unable to stand apart from the project and look at it objectively and from a purely theoretical standpoint, I was also unwilling to try. However, I do not believe that I could have had a purely subjective view either. Although I consider myself to be qualitatively inclined, and thus more likely to rely on data-driven, inductive reasoning (i.e. building general conclusions from in-depth data analysis without reliance on previously built theoretical ideas and concepts), this project was grounded in my understanding that autistic

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[12] *Neurotype* is a category distinction separating people of various neurodivergencies and neurotypical (or non-neurodivergent) people (Fletcher-Watson *et al*. 2021); *cross-neurotype* describes the interaction between different neurotypes.

people are likely to need alone-time to support wellbeing, given that the difference in how we process social and sensory input is associated with disability in certain social environments. While I am primarily interested in the unique and personal relationships autistic people have with time alone, being able to quantify the ways that people spend time alone, and the associations between this time and wellbeing, has value in terms of impact.

When neither objective, hypothesis-led, deductive reasoning or subjective, data-driven, inductive reasoning is of sole methodological importance in a study, a third option is available. An intersubjective viewpoint - which recognises that meaning is socially mediated through interaction - connects theory and data through abductive reasoning, i.e. making logical inferences from the data (Given, 2008). Researchers relying on abductive reasoning use their own expertise and intuition in combining qualitative and quantitative approaches to produce findings that can be considered the best available at the time, while simultaneously acknowledging that understandings may still be incomplete (Wheeldon & Åhlberg, 2012). Taking an intersubjective stance (i.e. that social and cultural contexts influence knowing) is common in mixed methods research and supports a pragmatic approach, which aims to draw transferable conclusions over generalisable or contextual inferences (Wheeldon & Åhlberg, 2012). The next section of this chapter describes the pragmatic approach I took in my mixed-methods research.

A pragmatic approach

In Chapter Two I introduced literature describing how various social and sensory environments can either reduce or trigger physical, mental and emotional overwhelm for autistic people. This environmental impact on autistic people is captured by Beardon's (2017) principle 'Autism + Environment = Outcome'. For my PhD research I sought to explore potential wellbeing benefits for autistic people from time spent alone in preferred sensory environments. Given that there is currently so little empirical research on autistic wellbeing within the Neurodiversity Paradigm, a pragmatic approach felt the most appropriate to me in answering the research questions.

Pragmatism marks a move away from the realist task of understanding the 'real world' in favour of understanding human experience and documenting how reality features in our daily lives (Salkind, 2010; Searle *et al*., 2004). Pragmatists are less concerned with the recognition of singular or multiple realities, and more with identifying the best practice for collecting data to answer any particular research question, and with translating the research results into action designed to address real-world problems (Creswell & Plano Clark, 2018; Salkind, 2010). Rather than being tied to particular philosophical frameworks or research methods, pragmatism focusses on the practicalities of answering the research question by whatever means (or methods) work best, and is interested in the practical applications of the research (Creswell & Plano Clark, 2018; Creswell, 2017; Biesta, 2010).

Combining quantifiable, empirical data with qualitative lived-experience data supports the pragmatic researcher in gaining a better understanding of a phenomenon (Wheeldon & Åhlberg, 2012). As such, dichotomies such as quantitative/qualitative methods, postpositivist/constructivist worldviews, objective/subjective knowledge and deductive/inductive practices are abandoned (Creswell & Clark, 2018; Biesta, 2010), and instead the focus is on whether the findings can be transferable rather than purely contextual or purely generalisable (Morgan, 2007). Using multiple methods of data collection to answer the research question is well suited to a pragmatist worldview; and is also able to combine contrasting perspectives on the question of bias: from the value that qualitative research traditions may place on the researcher's background and reflexivity, to the quantitative tradition of minimising the potential for researcher bias (Creswell, 2017; Plano Clark & Ivankova, 2016).

Within an underlying pragmatic philosophy, my approach to developing both personal understanding and research practice is informed by theoretical models, assumptions about the nature of a substantive topic (Plano Clark & Ivankova, 2016). These theoretical models, each of which I have presented in Chapter Two, are: the Social Model of Disability, which emphasises disabling effects of the social environment (Oliver, 1998); the Neurodiversity Paradigm, which argues against there being any one type of 'normal' brain or mind (Walker, 2021); Monotropism, which describes the autistic tendency for hyper-awareness within an attention tunnel (Murray *et al*., 2005) and the Double Empathy Problem, which explains breakdowns between autistic and non-autistic understandings and communication as situational rather than a deficit within the autistic person (Milton, 2012). As such, this research moves away from cognitive theories, such as the Theory-of-Mind, Systemising/Empathising and Extreme Male Brain models developed by Baron-Cohen (see Chapter Two), which dominate autism health and wellbeing research but have arguably caused a great deal of harm to the autistic community. Instead, this study favours theories with a more emancipatory focus which, as yet, have little in the way of empirical data in the literature (which is likely to reflect funding practices) but have been developed through emic understandings and are supported by autistic people, including those in the autistic academic community.

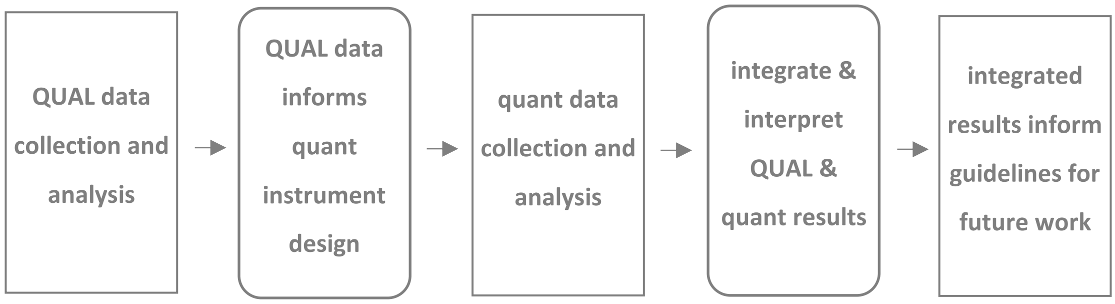
A pragmatist approach is ideally suited to a mixed-methods research design in that both qualitative and quantitative data are collected and analysed, and the results integrated to provide actionable results (Creswell & Plano Clark, 2018). The next section of this chapter outlines my mixed-methods study design and introduces my rationale for including a community advisory group.

3.2 Mixed methods research design

Sequential exploratory design

With a lack of closely associated literature available to inform the design of a quantitative data collection instrument, I felt it important to first elicit in-depth, inductive, qualitative data to help inform quantitative, deductive-led data collection. As such, I used an exploratory sequential mixed methods design intended to first explore the phenomenon of autistic adults using time alone to improve their wellbeing, and then to assess the extent to which the initial qualitative findings might be generalised to an adult autistic population. This study design allows researchers to explore a phenomenon in some depth before expanding the findings to a larger population and, although a sequential study can be time consuming, the predictability of the study's development makes it easy for one researcher to implement (Teddlie & Tashakkori, 2009).

Figure 3.1 depicts the flow of research for this study. It also indicates how the exploratory nature of this study gave the initial qualitative phase a greater emphasis in addressing the study's research aim by using uppercase letters for the qualitative work, using notation originally conceived by Morse (1991) and subsequently used in later mixed methods literature.



Procedures

Purposive sampling (n=16) Semi-structured video interviews Reflexive Thematic Analysis using NVivo software	Use qualitative findings to inform development of a quantitative instrument	Purposive and snowball sampling Excel used for descriptive analysis with 267 Questionnaire 1 and 202 Questionnaire 2 responses SPSS software used for multivariate regression on 146 sets of Questionnaire 1 & Questionnaire 2 responses	Discuss how qual phase informed quant development. Discuss whether quant phase suggests validity of qual themes	Develop recommendations for future policy, practice and research around autistic wellbeing and alone-time with community advisory group

Products

16 transcripts 4 themes	2 questionnaires	Descriptive statistics Regressive statistics	Discussion of integration	Recommendations

Figure 3.1: Procedural diagram depicting flow of research in the study's exploratory sequential design (QUAL → quant = explore and generalise findings)

For the initial qualitative phase I took a broadly constructivist approach, which explores meaning in context, described by Braun and Clarke (2021a, p. 174) as "*the consequences and implications of meaning-making*". After conducting 16 semi-structured interviews with autistic adults, I used Braun and Clarke's Reflexive Thematic Analysis (Reflexive TA) to explore how the participants described their realities in the context of spending time alone. Within Reflexive TA, the researcher is understood as part of the data production process, co-creating the meanings with participants and engaging with the data reflexively (Braun & Clarke, 2021a). I generated four themes from the data, which answered RQ1 in full, and qualitatively answered RQ2.

For the quantitative phase (to be discussed in Chapter Five) I administered two quantitative questionnaires, of which the second was sent to respondents two weeks after they had completed the first questionnaire. A total of 267 Questionnaire 1 responses and 146 Questionnaire 2 responses were eligible for statistical analysis. My descriptive analysis of the survey data (discussed in Chapter Six) quantitatively answered RQ2, and my correlation analysis fully answered RQ3.

In Chapter Six I also discuss the integration of the phases with reference to Plano Clark and Ivankova's (2016) rationales for mixed-methods research, including offsetting strengths and weaknesses, triangulation, complementarity, development and social justice. Separately analysing qualitative and quantitative data and then integrating findings, is a common approach in public health research (Bird, 2020). On completion of this integration, I discussed my findings with a community advisory group. The group then created a set of recommendations intended to inform future policy, practice and research on alone-time in the context of autistic wellbeing. These recommendations are presented and discussed in Chapter Seven.

Community advisory group

This study was designed to have a positive impact on the wellbeing of autistic, and thus, marginalised individuals and so it was important to involve other community members to help ensure that the study design, procedures and output would be accessible for participants, respectful of wider community views and relevant to community needs (Fletcher-Watson *et al.*, 2021). Nicolaidis *et al.* (2019) outline levels of engagement suitable for different types of participatory projects, including equal partnership, collaboration and consultation. For the current study I used a consultative model, for which a small autistic advisory group (CAG) was consulted throughout the project, but was not deeply immersed in the research, as modelled by autistic researcher den Houting (2020) in her work on participatory projects. I took care to avoid tokenising the participatory group's role (Nicolaidis *et al.,* 2019) and carried out all requested adjustments to accommodate individual requirements (den Houting *et al*., 2020) including emailing materials and detailed meeting schedules in advance of meetings so that members wouldn't feel put on the spot when asked for input.

Advisory groups include members of the marginalised community being studied, but should also be chosen by the researcher as those who have in depth knowledge of the research issues (Aidley & Fearon, 2021; Nicolaidis *et al*., 2019). I identified members for the CAG based on their lived experience of being autistic, prior engagement with emancipatory autism research, and relationship to the study's aims. I knew some of the members prior to inviting them to take part, and some I was aware of through social media, but had not previously spoken directly with them. At the study outset the group comprised of: Dr Ruth Moyse: an autism and education researcher using mixed methods and participatory frameworks; Michelle Parsons: a certified forest-bathing guide, with interests in neurodiversity and wellbeing; and a third advisor (name withheld), an advocate for racial, ethnic, cultural and socioeconomic diversity in autism representation. Due to reasons external to this study, the third advisor left during the qualitative phase. A PhD candidate researching the stigma of learning disabilities (name withheld) then joined the group before planning of the quantitative phase took place, but left before the group collaborated on creating policy, practice and research recommendations. Finally, Krysia Waldock, a PhD candidate researching belonging and faith in an autism context, joined the group to collaborate on the recommendations.

Initial introductions to the project and its aims were made via email. I sent the project registration document and an outline of the same document in lay language, with a clear summary of what the group's role would be throughout the project. I also made it clear that any accommodations needed would be considered and that these could be discussed at any point, and I made particular efforts towards making sure that all written communication was clear and that processes were transparent. We had four video meetings over Microsoft Teams during the project, and the input from the CAG is clearly described throughout this thesis.

The first half of this chapter has discussed the methodological considerations for my PhD research in its entirety, from my positionality and theoretical framework, through to the research design and inclusion of the CAG. For the rest of this chapter I detail the methods for the qualitative phase, including the ethical considerations, data collection and data analysis.

3.2 Qualitative phase: data collection

The next section of this chapter discusses the considerations made and methods used for the qualitative phase of the research project for which I collected data from 16 adult autistic participants through either video-interview or synchronous text-based interview (according to accessibility needs/preference). My semi-structured interview schedule (Appendix A) and Reflexive TA of the resulting data were intended to explore participants experiences, needs and understandings around (1) how they chose to spend time alone, (2) where they chose to spend time alone, and (3) the benefits of this time and space alone. Prior to this study, most of what we knew about these questions could only be answered by anecdotal evidence; the literature had not yet explored this area of autistic wellbeing.

Ethical considerations

Research ethics principles govern the design, management and conduct of research and are designed to protect the dignity, rights, safety and wellbeing of participants, researchers and society (Cascio *et al*., 2021b; McClean, 2020). The Economic and Social Research Council (ESRC), the funders of my PhD study, set out principles of good practice for social research:

> *"(1) research should aim to maximise benefit for individuals and society and minimise risk and harm, (2) the rights and dignity of individuals and groups should be respected, (3) wherever possible, participation should be voluntary and appropriately informed, (4) research should be conducted with integrity and transparency, (5) lines of responsibility and accountability should be clearly defined and (6) independence of*

> *research should be maintained and where conflicts of interest cannot be avoided they should be made explicit"* (ESRC, 2021).

All universities are required to have a research ethics framework and the University of the West of England (UWE), with whom ethical approval was applied for and granted (see Appendix B, and also Appendix C for my data management plan), has six principles of good ethical research which are closely in line with those of the ESRC. Similar ethical frameworks include those by the British Psychological Society (BPS) whose four principles are those of (1) respect for the autonomy, privacy and dignity of individuals, groups and communities, (2) scientific integrity, (3) social responsibility, and (4) maximising benefit; and minimising harm (BPS, 2021); and those by the British Educational Research Institution (BERA), who emphasise these same principles but also add inclusivity of different interests, values, funders, methods and perspectives (BERA, 2018).

Cascio *et al*. (2020) consider that the historical disenfranchisement of autistic people raises the need to re-articulate a commitment to high ethical standards. Following extensive community and academic discussion, the Academic Autism Spectrum Partnership in Research and Education (AASPIRE) created practice-based guidelines for the inclusion of autistic adults in research which make clear the importance of (1) avoiding coercion and exploitation while maximising autonomy and inclusion, (2) ensuring that the consent process is accessible, (3) offering multiple modes of participation to include participants with differing needs, (4) assessing the validity of instruments designed for other populations, (5) creating accessible interview guides, and (6) using proxy reporters only when necessary (Nicolaidis *et al*., 2019). Each of these principles are implicit in ESRC and UWE guidelines, but the specificity of the AASPIRE guidelines clarify the necessity of considering accessibility requirements towards ensuring 'autonomy, privacy and dignity', and of 'maximising benefit and minimising harm'.

Considerations around vulnerability, consent and power dynamics

Applying for ethical approval when researching any population includes questioning whether the participants are, or might be, considered vulnerable; but the nature of vulnerability should be considered within the context of the research. The concept of vulnerability can be linked to the capacity for giving informed consent, and so people considered vulnerable include those susceptible to coercion or undue influence, or those who may not understand the implications of participating in a research project (Aidley & Fearon, 2021). Within the context of this study, I considered that all the qualitative participants had the capacity for and the opportunity to give informed consent for the following reasons:

1. all participants for the qualitative phase were recruited via social media and thus were able to sign up for and use social media in the first instance
2. signing up for and giving consent for the current study necessitated following an online link to a webpage outlining the study before emailing me directly to express interest, and then completing an involved process of completing an online consent form and filling in a preparation sheet
3. all the research documents were designed to be widely accessible (described later in this chapter section)
4. throughout the interviews I continually checked for ongoing consent, using jargon-free questions such as “are you happy for us to keep going?” (Cascio *et al*., 2021).

A second concept of vulnerability concerns power disparities, and so the participants’ circumstances should be considered in the context of the research relationship (Aidley & Fearon, 2021). All the participants were autistic, but as a member of that same marginalised community my experiences and understandings of autism reduced my position of power; as reflected in Pellicano’s *et al*. (2022) qualitative work with 25 autistic participants which found that interviewees felt supported, safe and understood when interviewed by an autistic researcher. While my role as an interviewer did automatically put me in a position of power I took care to flatten this power dynamic through my own understanding that the participant’s contribution to the research was expertise over their own experiences and understandings (Karnieli-Miller *et al*., 2009). Some interview participants were previously known to me but I do not believe that this contributed towards any meaningful power imbalance (discussed later in this chapter).

Participant information sheet, research privacy notice and consent form

I used UWE templates to create the participant information sheet (Appendix D) and consent forms (Appendix E, with separate forms for video interviews and text-based interviews), and checked these documents against guidelines suggested by AASPIRE and the Autistica Research Toolkit (Nicolaidis *et al*., 2019; Autistica, 2021). While it should not be assumed that autistic participants are more likely to have an impaired decisional capacity than research participants who are not autistic, any process seeking informed consent needs to be accessible, particularly considering that participants may have challenges with literacy or language pragmatics (Cascio *et al*., 2021; Nicolaidis *et al*. 2019). I wrote the documents in clear, concrete language and clearly formatted them to allow (1) ease of reading, and (2) fluent text-to-speech functions such as Microsoft Word's Read Aloud feature. Once drafted, any accessibility issues were resolved using Microsoft Word's accessibility check feature. The CAG checked both documents for clarity in terms of (1) what the research was, (2) what was expected of participants, (3) what they could expect from the process, and (4) how their data would be used and protected. I made minor changes throughout the documents as a result of the CAG's recommendations, particularly in terms of clearer and more precise wording. The research privacy notice (Appendix F) was also adapted from a UWE Bristol template, but very little change could be made to improve accessibility, beyond reformatting the document, without changing the meaning. Finally, the documents were sent to, and approved by UWE's faculty research ethics committee as part of the ethics application. As all interviews were to be held online, the consent forms were recreated in Qualtrics, with simple yes/no options for each consent point.

Data collection

Case selection

Data collection procedures differ in qualitative and quantitative research, and so mixed methods studies need to address strategies such as sampling and sample sizes within the context of the mixed methods design (Creswell & Plano Clark, 2018). Qualitative sampling purposively selects cases in order to inform rich understandings of the research question and so, sample sizes should be dependent on the research question, purpose of the study and methodology, rather than attempting to represent a population (de Viggiani, 2020). In the next two paragraphs I justify the number of participants recruited before I describe the recruitment strategy itself.

Defining sample sizes *a priori* in inductive and exploratory qualitative research can be problematic as we cannot know the themes in advance (Braun & Clarke, 2021; Sim *et al*., 2018). Equally, while recruiting until the researcher considers that the codes are saturated is suitable for many qualitative methodologies, Reflexive TA considers that themes are generated through analytic engagement with the data, rather than excavated or emergent from the data, and so this approach is not considered appropriate for Reflexive TA (Braun & Clarke, 2021b; Terry & Hayfield, 2021). Further, exploratory analyses are not intended to cover the whole range of phenomena, rather to present selected patterns which attend to the study's aim (Malterud *et al*., 2021). Low (2019) suggests letting go of the assumption that saturation can only be achieved when there is no new information; as long as new data is collected there will always be further theoretical insights.

Malterud *et al*. (2016) propose the concept of 'information power' which considers that the study aim, sample specificity, use of established theory, quality of dialogue, and analysis strategy should guide sample sizing. The current exploratory study had a relatively broad aim, did not require particularly specific experiences (beyond being an autistic adult living in the UK), and was based on theoretical concepts which are not widely established; all of which suggested needing a larger number of participants. However, the understanding that I would be able to rely on strong and clear communication between myself as an interviewer and my participants (based on Milton's DEP, as described in Chapter Two), and thus my expectation of detailed and rich data, suggested that fewer participants would be advantageous in order to capture nuance and individual context. Braun and Clarke (2013) consider 10-20 interviews as suitable for study within a large project and I considered that a sample size of 15 would be large enough to demonstrate patterns across the dataset but small enough to focus on individual experiences (Braun & Clark, 2013).

Recruitment

Research with adult populations allows for a wider diversity of participants by enabling the inclusion of late-identified individuals, who would not have been identified as autistic in childhood due to biases in earlier versions of the diagnostic criteria (Tint *et al*., 2018; Happé *et al.*, 2016). Adult autism studies commonly recruit purposively via social media where the range and diversity of genders, ages, ethnicities and incomes are likely to be varied; for this study I opted to recruit in the same way. I had planned to gradually share my recruitment page over a number of platforms and days, starting with the inclusion of links to this page within Twitter posts. However, it took less than 48 hours for sixteen participants to email me in response to my initial tweet (I only have a moderate twitter following but the post was retweeted multiple times resulting in nearly 13,000 views). After the initial introductions were made, two people did not sign the consent form or reply to further emails so I posted an additional tweet specifically requesting autistic men or autistic non-binary people to participate as they were less represented in the sample. Subsequently two replied to this later tweet and one of the earlier respondents who had previously not replied to my emails asked to be included, giving a total of 16 participants. Two of the final participants were known to me, and I had had brief online interactions with two others.

When I posted the original tweet I also asked several UK based individuals advocating for autistic people of colour if they would share the recruitment page to help ensure that the study would reflect the needs and experiences of the wider autistic community. Autistic people who are further marginalised due to skin colour and cultural differences are not well represented in autism research (Cascio, *et al.*, 2020 & 2021a). Anecdotally it is often argued that autism does not have anything to do with race. However, accounts from autistic people of colour - such as within the anthology “All the weight of our dreams: on living racialized autism” (Brown *et al.*, 2017) - clearly describe how autism is experienced very differently by those who are additionally marginalised by skin colour or ethnicity. Research also shows that autistic people of colour are often understandably reluctant to participate in studies run by white researchers who have not previously formed strong, authentic relationships with relevant community-based organisations (Aidley & Fearon, 2021; Shaia *et al.*, 2019). One advocate subsequently shared my tweet and some did not reply, however a few declined, explaining that with so few people of colour identified or diagnosed as autistic, the burden on those individuals to participate in autism studies is already too high. I respected their answer and ceased actively ‘chasing’ autistic people of colour to participate.

Posters and digital posters are not always easy to read and often lack read-aloud functions. Instead, my tweets linked directly to a stand-alone page on my personal website, formatted to be easily read on phones, tablets or desktops, and with a text-to-speech option. The web page outlined the study and stated that participants could either have a formal diagnosis or have self-identified[13]; that they must be from the UK, and that they must be at least 18 years old. No participatory incentive was offered. Those that were interested in taking part followed the email link from the webpage, and were sent the participant information sheet and research privacy notice in return. If they confirmed that they still wished to take part I asked them to sign a consent form on Qualtrics, and gave them a link to a shared online folder, accessible only to that individual and myself. Each folder contained a preparation sheet to complete before the interview date (Appendix G), and copies of the participant information sheet, research privacy notice and the consent form for easy reference. Participants were also asked to suggest three possible times and dates during the following two months for the interview which I used to send calendar invites via Microsoft Teams.

Participant demographics

Using a simple open response form as part of the preparatory sheet, participants were asked to specify their gender, age and ethnicity. They were also asked to choose their own gender- and ethnicity-appropriate pseudonym. The participants were informed that pseudonyms and ages would be provided alongside any quotes published.

- 11 identified as female, 4 as male and 1 as non-binary
- 4 were aged between 18-30, 6 were in their 40s, 5 in their 50s, and 1 was in their 60s
- 1 identified as Black British, 1 as Mixed Heritage, 11 as White British, 1 as White Irish, 1 as White Polish and 1 as White Welsh
- The participants chosen pseudonyms were: Tom, Sarah, Lori, Maria, Daisy, John, Flavia, Jack, Susan, Bill, Cody, Jae, Ceri, Kirsty, Carys and Emily.

Participants were not asked to provide any further demographic details such as the number of those living in their household, the number of people being supported or cared for by the participant, household income, educational level reached, employment status, types of

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[13] Obtaining a clinical diagnosis through GP referral can take several years, or cost thousands of pounds if sought privately. Further, many autistic people choose not to pursue a pathologised diagnosis of Autism Spectrum Disorder with no guarantee of support once a diagnosis is in place. An increasing number of researchers allow participants to have self-identified (such as Botha *et al.*, 2020).

disabilities experienced, or whether the participant had additional support. However, it was apparent in the interviews that there was a wide range within each of these demographics.

Online interviewing

Justification for and planning for online interviewing

Video interviews can address a number of accessibility issues which may otherwise make participation difficult or even impossible (Aidely & Fearon, 2021): the participant doesn't need to leave their own home, social distancing is automatic, and captioning can be included. While phone interviews are often offered for remote interviews, many autistic people, myself included, find communication without visual context inaccessible. I also offered interviews in the form of synchronous text-based chats as many autistic people find spoken communication difficult (Zisk & Dalton, 2019; Howard & Sedgewick, 2021).

Many autistic people need time to process communication (Howard & Sedgewick, 2021; Beardon, 2017) and so my original study design was to use the diary-interview method as pioneered by Zimmerman and Wieder (1977). Researcher-directed diaries, as daily written entries over the course of the week, were to be used to help participants' recall for the interviews and allow the interviews to be grounded in the participants' own textural data (Elliot, 1997). However, the CAG felt that daily diary entries might prove time-consuming and stressful for the participants and so we created a short online preparation sheet (Appendix G). This sheet, created in a OneDrive folder and only shared between myself and the participant to maintain data protection, could be accessed as often as the participant needed to; and I only looked at their answers a day or two before the interview so that they didn't feel I was 'looking over their shoulder'. Providing questions and a loose structure in advance gave the participants a chance to process the questions and, to a certain extent, script their answers if desired. The CAG suggested the design of the sheet, helped define the questions and piloted it for feasibility and relevance. This sheet had multiple uses including:

1. asking for basic, relevant demographic details and explaining how those details would contribute to the research ethics
2. asking the participant to provide their own gender- and ethnicity-appropriate pseudonym to enable them to take ownership of their contribution to the study (Allen & Wiles, 2016)

3 giving some detail on how the interview would run and reminding the participant that they could ask for accessibility accommodations at any point, including taking a break or asking me to rephrase questions

4 providing space for the participants to process their thoughts around the questions to be asked in the interviews, and to highlight what they would like to be asked about

5 allowing me to ground my interview questions in the information already provided by the participant

6 facilitating easier participant-recall in the interview

Several participants mentioned that they appreciated knowing the subject matter in advance, felt that the process relieved anxiety around what might be asked in the interview, and felt that being given time to process their thoughts meant that their input was valued. However, some participants filled in their sheets well in advance of the interview and so had forgotten what they had written, and some requested reminder links as they couldn’t find their way back to the OneDrive folder. While the shared document system was convenient for myself and helped to strengthen data protection, it was not necessarily a user-friendly option for the participants.

Few accessibility accommodations were requested. A few participants mentioned that they might need to take a break if they got tired or experienced visual strain, and so I took care to keep those interviews short. One participant was worried that they might go off topic and requested that I bring them back to the question asked if necessary, a few were worried that I might take their long pauses or bluntness for rudeness, and one asked to be emailed with a reminder for the interview. I reassured each of them in advance of the interviews that I would follow their requests, and then reiterated this reassurance at the beginning of the interviews.

Carrying out the interviews

Those opting for video-interviews were interviewed and recorded via Microsoft Teams. Microsoft Teams allows for captioning, which one of the participants used. Two interviewees opted for synchronous text-based interviews which took place via a shared Word file in OneDrive, allowing us each to view the other’s communication as it was written. Prior to the video-interviews, participants were asked to make sure that they had sufficient internet bandwidth to enable clear visual and audio and I did the same. On the day, I set my camera up so that they would easily be able to see me, ensured that I would not be interrupted, and checked that each participant could easily see and hear me. At the outset of all interviews I reminded participants what the study was about and how the interview would run. I also ran through the consent points and emphasised that they did not have to answer any questions they were uncomfortable with and that they could still withdraw at any point, or even redact any answer they had given that they were not happy being shared publicly. No participant withdrew or asked to have any part of their interview redacted.

All interviews ran between 30 and 60 minutes. I gave minimal prompts based on the interview schedule, and the participants' completed preparation sheets, allowing the participants to talk freely about what was important to them. Interviewing appeared to be a relaxed and enjoyable experience for the participants, all of whom were keen to describe their needs and experiences. I felt that the participants knowing in advance that I was also autistic facilitated conversations, with most assuming shared understandings and experiences and referring to common 'inside jokes' around the challenges of being autistic in a non-autistic world. Some video participants looked straight to camera, others looked away, several stimmed with fidget toys or pens while talking. Although some participants expressed sadness when reflecting on experiences when they weren't able to access time alone, nobody appeared distressed at any point, with the exception of one participant who was interrupted by a family member during the interview (acknowledging her distress and giving her time to recover and collect her thoughts meant that the rest of the interview went smoothly).

Researchers should be mindful of the inherent power relationships in interviewing, with the interviewer typically being viewed as an expert and therefore in control of the interview (Braun & Clarke, 2013). However, autistic people are commonly considered to be less observant of social hierarchies and the participants appeared confident in their own expertise; three participants told me that it was not their 'first rodeo'. Interviewers and interviewees who are previously acquainted may find themselves negotiating new relational identities (Garton & Copland, 2010); however, beyond the initial introductions at the beginning of the interviews, I did not notice any discernible difference in interactions between interviewees that were known to me and those that weren’t. In line with Braun & Clarke (2013) recommendations for ‘acquaintance interviews’ I avoided prompting to elicit information that I had known previously. Although it was occasionally frustrating knowing that they could have discussed certain views and experiences that I felt could be valuable to my research, I do not believe that it would have been ethical to use prior knowledge of these participants to elicit information that they hadn’t chosen to discuss in a research context.

I only ran into minor problems with online interviewing, either due to participants’ connection problems and limited bandwidth, or participants being unsure how to access the meeting. Each of these was easily resolvable or could be worked around. Both of the text-based interview participants found that their cursors sometimes spontaneously moved while typing so that new text was inserted into a previous sentence but they felt this to be only a minor inconvenience. To indicate when either myself or the participants had finished asking or answering a question we typed our initials to make it clear that we had finished ‘speaking’, rather than just pausing before starting a new sentence. While not part of the analysis, it was interesting to reflect on the wide range of speech patterns from the video-participants: from short answers to longer monologues; from eloquent and rounded answers to long pauses, false starts, repeated words and phrases, wrong words and filler words; and from direct answers through to describing through storytelling. From a personal perspective, hearing the difficulties some participants had with forming clear sentences but not understanding them any less, was validating as my own use of speech is very similar.

Transcription

I transcribed the interviews myself, omitting introductions, endings, filler words, interruptions (such as deliveries, pets and, on one occasion, livestock entering the participant’s home), false or repeated starts to sentences (common speech patterns for many autistic people), data that might make the participant easily identifiable, and my own words only where they were not relevant and did not influence the interview data. I then saved the transcriptions to OneDrive for data security and deleted all vocal recordings. The text-based interviews only required minor ‘tidying up’ to correct typographical errors, and remove introductions and the initials used to indicate the end of a question or answer.

3.4 Qualitative phase: analysis

Following my transcription of all the interviews, I used Braun and Clarke's Reflexive TA to identify meaningful themes in the dataset (Braun & Clarke, 2021a), as used by other qualitative studies on autism and mental health (including Raymaker, 2020; Stagg & Belcher, 2019; Crane *et al.*, 2019; Camm-Crosbie *et al.*, 2018). Reflexive TA as a method is underpinned by theoretical assumptions and treats researcher subjectivity as a resource, acknowledging that the researcher and participants will impact on each other's understandings during data collection and analysis. The flexibility of Reflexive TA supports identifying both latent and semantic meanings, and offering both descriptive and interpretive accounts of the data. Braun and Clarke (2021a) provide a clear set of guidelines for analysing the data: a six-phase recursive process designed to facilitate deep engagement with the dataset. The phases (1) data familiarisation, (2) data coding, (3) initial theme generation, (4) theme development and review, (5) theme refining, defining and naming, and (6) writing up; encourage the researcher to move back and forth between phases to deepen understandings and interpretations of the data. The remainder of this chapter charts how I used this recursive process to analyse my interview data.

Phase one: familiarisation

Thematic analysis requires the researcher to become actively engaged with the data set; the first phase, reading - and re-reading - with the purpose of 'immersion in the data', is that of familiarisation (Terry & Hayfield, 2021). I undertook this by transcribing the interviews myself, and then reading through the transcripts a number of times. Braun and Clarke (2021a) describe the active process of engagement with the data: asking questions about how individual participants make sense of what they are discussing, how socially normative their depictions might be, and how their experiences and assumptions reflect those of the researcher. While some texts on Reflexive TA recommend journaling the process of working through the data I found that this blocked and slowed my reflexive process. Instead, reading through the entire data set and then going for a walk enabled me to think more fluidly about meanings and patterns within the data. Being reflexive in this way also gave me a chance to 'internalise' the data, noting where participants' experiences and understandings reflected or contrasted with those of my own. I repeated this process a few days later.

Phase two: coding

Coding is a more systematic and rigorous way of engaging with the data than familiarisation by breaking the data up into manageable ‘chunks’ and then naming these chunks (Terry & Hayfield, 2021). Braun and Clarke (2021a) describe codes as heuristic devices - tools to aid rich and nuanced understanding. During a subsequent read-through of the data set I made a rough list of over forty possible codes. Although these were primarily inductive - informed by the data rather than theory - it is important to note that being a part of the data collection - interviewing as an autistic researcher - meant that the process of coding itself at times leaned towards a more deductive or researcher-led orientation; as described by Braun and Clarke, “*you cannot enter a theoretical vacuum when doing TA*” (2021c, p.331). My coding was mostly at a semantic, or surface level of the data; capturing or summarising points made by participants. However, some codes were more latent in nature, drawing on monotropism theory, and prior knowledge of existing research into autistic masking.

I was the only person to code the data and, given the subjective nature of Reflexive TA, Braun and Clarke consider this to be usual and good practice. However, I shared my initial list of codes along with the dataset with my supervisor FS, who advised me that some of my codes could be combined. For example, the code ‘*not getting alone-time leaves me exhausted’* was made redundant by another code ‘*alone-time recharges my energy’*. On re-reading the interviews with the list of codes it then became apparent that some of the codes needed more nuance in order to capture more meaningful content from the data. Thus, ‘*alone-time recharges my energy’* then re-expanded to become two new codes: ‘*alone-time relieves sensory and social exhaustion’* and ‘*alone-time recharges batteries’*.

Once all the transcripts were uploaded to the computer-assisted qualitative data analysis software NVivo, I made several passes or ‘coding runs’ through each of the interviews over the course of a fortnight. Some researchers advocate for manually coding, due to being distracted by numerous software functions and a sense of engaging less with the data through a screen (Braun & Clarke 2013; 2021a). However, after some initial problems with getting used to the software I found the process to be less visually overwhelming than my prior experience of manually coding, and I was not distracted as I only used the most basic software features. As I coded the datasets, I continually refined the codes and the code descriptions as I went to make sure that they were meaningful and that they would help to answer my research questions for the qualitative phase. Despite Terry and Hayfield's (2021) warning that this level of active engagement would be tiring, I was still surprised at how taxing coding actually was, but felt the level of engagement required was ultimately rewarding as I became increasingly immersed in the data. I stopped coding once I felt that I might run the risk of over-tweaking the codes and labels (Braun and Clarke, 2021a). The final codes can be seen in Appendix H.

Phase three: initial theme generation

In Reflexive TA, themes should move beyond description and towards developing conceptual ideas that hold codes and data together while telling the story of the data to answer the research question (Terry & Hayfield, 2021). The central organising concept of each theme should capture something meaningful, be coherent and have clear boundaries (Braun and Clarke, 2021a). Reflexive TA highlights the tentative nature of initial themes (also known as candidate or prototype themes), and how the development of these initial themes enables enhanced engagement with the data (Terry & Hayfield, 2021).

Constructing themes may take two primary pathways: (1) 'clustering': grouping codes of equal weight together according to their similarity, and (2) 'promoting': changing the status of dominant codes to a candidate theme (Terry & Hayfield, 2021). To identify the themes, I printed a list of the codes, cut the individual codes out, and spent some time moving the codes around on a flat surface until I was satisfied with the groupings. None of the codes stood out as dominant within any of the groups and so I constructed the themes through clustering (Appendix H). While the generation of overarching themes or subthemes may provide rich structural complexity, Braun and Clarke (2021a) warn that this complexity may come at the cost of losing analytic depth. I did not feel that adding sub-themes would contribute towards additional interpretation or understandings.

Terry & Hayfield (2021) warn against relying on domain summaries or 'bucket themes', broad groupings of data based around ideas that may have pre-existed before analysis. As the four themes I had generated felt fairly obvious to me, I had some personal concern that my prior interest and experience may have led towards domain summaries. However, as I reflected on the process I had taken to generate the initial themes, I considered that working though the staged structure of Reflexive TA had helped guard against this. Rather than generate clusters related to specific questions, each of the clusters helped to answer several aspects of the exploratory nature of the study aim.

Phase four: developing and reviewing themes

Once I had identified the initial themes, I re-engaged with the codes and the coded data extracts to ensure that I hadn't let the themes 'run away with me'. Braun and Clarke (2021a) ask the researcher to reflect on (1) whether they can identify the boundaries of the theme, (2) whether there is enough meaningful data to evidence the theme, (3) whether the data within each theme might be too diverse or wide-ranging, and (4) whether the theme conveys something important. The boundaries of each theme appeared clear, focussed and important to me but I was unsure whether I had enough meaningful data to evidence the fourth theme, particularly as it was made up of only two codes. On re-coding for this theme, I noted that not only was there was more data than I had originally identified, but that the latent nature of the codes, 'socialising must be balanced with alone time' and 'wanting to be with others' meant that the chunks of text were not often clear and so I had not physically coded as much as I could have. After recoding, there was easily enough data to evidence the fourth theme. Once I had rectified this I experimented with different clustering possibilities but was ultimately satisfied that Braun and Clarke's four review and development questions (above) could be answered in the affirmative.

Phase five: refining, defining and naming themes

Braun and Clarke (2021a) ask the researcher whether they can clearly define (1) what the theme is about, (2) what the boundary of the theme is, (3) what is unique and specific to the theme and (4) what each theme contributes to the analysis. Terry and Hayfield (2021) outline the purpose of these definitions as (1) helping to further refine the themes, (2) confirming that each theme has enough conceptual and story-telling depth and (3) clarifying the relational shape and overall story of the themes. I found that writing the theme definitions in line with Braun and Clarke's recommendations, and Terry and Hayfield's reiteration of these recommendations, was a useful structural process; a reminder of the reflexive aspect of Thematic Analysis and a useful strategy for clarifying my thoughts. Additionally, these definitions provided a useful basis for writing a lay summary of the themes for the participants and for presenting an early summary of findings to various groups.

Theme names should be informative, concise and catchy and act as a clear signpost for the reader (Braun and Clarke 2021a; Terry & Hayfield, 2021). As I have a particular fondness for alliterative groupings, the following theme names – along with brief definitions fitting the above criteria – were easy to generate. More detailed definitions are given in Chapter Four, which presents the findings of this phase.

Theme 1: Reacting to social and sensory overwhelm

Participants talked about the emotional and physical impact to themselves of not having access to time alone in spaces that didn't trigger sensory sensitivities. Without access to time alone, physical and social distractions built up and became increasingly difficult to process. Nearly all of the participants talked about how not getting a break from others could cause distress, exhaustion and feeling irritated, agitated and frustrated.

Theme 2: Retreating from social and sensory overwhelm

Participants talked about how they retreated from uncomfortable or disabling social and sensory spaces, where they retreated to, and why they retreated. They described how it was often necessary to create boundaries. Several talked about the importance of having control over their home environment. Unprompted, all but two of the sixteen mentioned that time alone was the only chance they had to be themselves as they didn't have to act a certain way to make others more comfortable.

Theme 3: Regulating, recovering and recharging

Participants talked about how they used time alone to regulate, recover and recharge batteries. Time alone provided the opportunity to either actively process thoughts and emotions that had built up during the day or, conversely, to dissociate from them – alleviating anxiety, worry and perseverant thoughts. In particular, most talked about immersing themselves in a special interest. This immersion bought joy, and the chance to shift focus away from things that were more problematic.

Theme 4: Ready to reconnect with others

Participants talked about how time alone supported an enjoyment of socialising. Some of the participants considered themselves to be sociable people, and several talked about how much they liked being with other people. Some social activities, which didn't revolve around face-to-face communication, made socialising easier. But without balancing social time with alone time, even these social activities were difficult.

Phase six: writing up

Braun and Clarke (2021a) describe how this final phase formalises the analytic process through further refining the themes to shape the detail and flow of the analysis, and also working to tell the whole analytic story. While describing the themes in greater detail, and using data extracts to demonstrate the validity of these themes, the reflexive and recursive nature of Braun and Clarke's TA meant that even during this final stage I still revisited the coding, made minor adjustments to the theme titles and observed small shifts in my interpretation of the data. In particular, I noticed how the analytic story was more dynamic than I had previously noted. To emotionally and physically regulate from the overwhelm caused by social and sensory environments, the participants had developed clear and purposeful strategies, so that they felt empowered to re-join social environments when desired.

All participants opted to receive a summary of the findings on completion of the qualitative analysis. Once I had completed a first draft of the analytic write up I sent a copy to the CAG members and to each of the participants. Although I had not asked for feedback, many of the participants emailed back to say that the themes were consistent with their individual experiences and that they looked forward to the completed study findings. I did not receive any negative feedback.

Chapter conclusions

This methodology chapter (1) described my positionality and pragmatic approach to the PhD research as a whole, (2) outlined the sequential exploratory mixed-methods research design, and (3) described the methodology for the qualitative phase of the research: the ethical considerations, data collection and analytic approach. Beyond detailing the methodological steps that I took to designing the study, collecting and analysing the data, I believe that this chapter demonstrates my commitment to ethically and sympathetically representing an area of wellbeing needs and experiences as voiced by members of the autistic community, from the research design, through creating accessible materials, to using an analytic style that allowed the themes to be predominantly shaped by the data, rather than theory.

Chapter Four: Qualitative Analysis and Discussion

> "It doesn't matter how you feel inside, you know? It's what shows up on the surface that counts. That's what my mother taught me. Take all your bad feelings and push them down. All the way down past your knees until you are almost walking on them. And then you'll fit in. And you'll be invited to parties. And boys will like you. And happiness will follow."
>
> - Marge Simpson (1989), The Simpsons, 1989

This chapter presents and discusses the findings from the qualitative phase of the mixed-methods research for which I used Reflexive TA to analyse the transcript data from sixteen interviews with autistic adults to construct four themes: (1) reacting to social and sensory overwhelm, (2) retreating from social and sensory overwhelm, (3) regulating, recovering and recharging, and (4) ready to reconnect with others. A thematic map (Figure 4.1) shows two additional aspects of the findings. Firstly, the dynamic relationships between the four themes suggest three potential pathways (indicated by the large arrows) from *reacting to social and sensory overwhelm* to *ready to reconnect with others* (i.e. themes 1-2-3-4; themes 1-2-4; or themes 1-3-4). Secondly, the impacts to and from the four themes (indicated by the small arrows) highlight how *reacting to social and sensory overwhelm* and *retreating from social and sensory overwhelm* could be seen as reactive states, influenced by external factors such as social and sensory input; while *regulating, recovering and recharging* and *ready to reconnect with others* could be seen as proactive states, with the individual feeling empowered to do what makes them feel happy and connected, such as engaging in flow-state activities or socialising with other neurodivergent people

Please note that the non-circular flow of the map is deliberate – Theme 4: *ready to reconnect with others* does not necessarily dictate a circular progression back to Theme 1: *reacting to social and sensory overwhelm*.

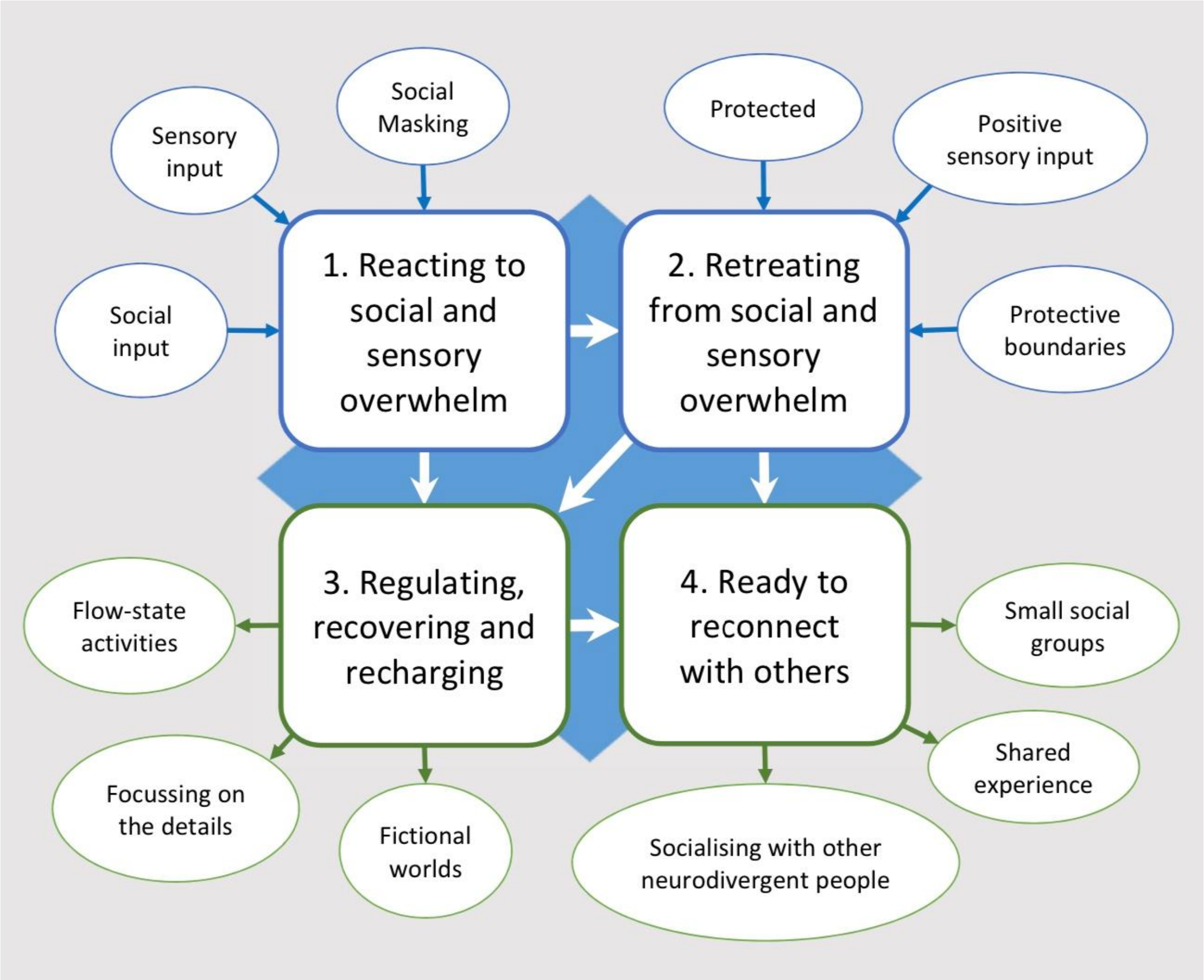

Figure 4.1: Thematic map showing (1) relationships between themes, and (2) impacts to and from themes.

4.1 Reacting to social and sensory overwhelm

The first theme describes how social input and certain sensory inputs were distracting and often, after intense or extended periods, left participants feeling completely overwhelmed. Social input, in the form of verbal and non-verbal communication, might provide challenges from one-on-one or group interactions; or from overhearing communication between others. Social input in itself was not necessarily problematic, but difficult, intense or extended periods of being in social environments such as family homes, workplaces or public spaces were physically and emotionally overwhelming.

> *"Other people, no matter how much you love them, are hard work on the whole to understand. And I can feel myself just losing power, just getting drained of energy."* (Flavia, 57)

Meanwhile, the participants' descriptions of negative experiences of sensory input in social environments included sounds that were too loud or distracting, and lighting that was too bright. Negatively experienced sensory inputs were harder to mitigate in social environments and so were compounded when also spending time with other people. Processing social input made simultaneously processing sensory information more difficult, and negative experiences of sensory input made processing social information more difficult.

> *"I struggle when there's background noise, with distant wooshing sounds and sounds like that. Voices particularly seem to cause me difficulty and if there's two people talking at once, I'm trying to separate the voices, I tend get the words they're both saying all jumbled up and I can't understand either of them."* (Sarah, 47)

Overwhelm, manifesting as exhaustion, anxiety, physical discomfort, confusion and difficulties with executive function, was experienced after periods of juggling social and sensory input. Many described the overwhelm they experienced from continued social or sensory distractions in metaphorical terms. Whether they had spent hours with several family members, uninterrupted days (such as during lockdown) with a partner, a working week in a busy workspace, or an evening in a social space, the resulting overwhelm was often felt as a physical sensation. Some described a feeling of dangerous internal pressure threating to explode or a *"traffic jam of processing"* (Emily, 27), and others as discomfort or even pain.

> *"Realising that if I don't get that time alone and if I'm having to mask, each have massive pressure. It's just* [mimes an explosion] *it's just when I can't just be."* (Lori, 53)

> *"That sort of tunnel vision thing begins to happen and there's tightness and the feeling that something is building inside and [I've] just got to do something with that because it's just going to burst… it's a clue that I need to stop."* (Daisy, 47)

> *"A visual representation would be like I have lots of little sharp-teethed creatures inside me, nibbling away and tearing tiny strips of my insides away."* (Jae, 58)

> *"…that twitchy, all edges thing of: I don't know what to do with myself, I need to do something with myself, I've gone sensory processing wrong, my skin feels wrong, everything feels a bit wrong, I'm all edges, I don't know what to do."* (Kirsty, 44)

Participants described feeling drained or exhausted from periods of social input even if they loved those people and enjoyed those interactions. Exhaustion was often associated with feelings of agitation, irritability or frustration, which might be directed at a particular person or group, the social and sensory environment itself, or internally. Trying to contain those strong feelings rather than snap at other people contributed to further exhaustion.

> *"I find myself becoming agitated and then frustrated if I don't have the space to myself for a really long time. I also get angry… So, it's mostly frustration and people starting to irritate me like it doesn't matter what someone does, it's just frustrating. Like everything is wrong and it's just really tiring."* (Cody, 20)

> *"If I know other people are around then, because I'm aware of them, they're distracting. It's harder to relax and it's harder to focus on everything else around me and I can get anxious around people and it feels too many people or they're too close to me and sometimes I can handle it better than others and sometimes I can't handle it at all."* (Sarah, 47)

For some participants, part of this energy depletion was caused by playing certain social roles that they felt were expected, whether by friends, colleagues, family, or people they didn't know. The more people they came into contact with during a situation or over a time period, the more they felt that they had to juggle the performance of different roles or personas.

> *"I find that making sure that I am the person I am for all of these people… all the aspects of me, it's sometimes a little bit more tiring than just being just me by myself. I have to be switched on and actively listening and many of the things that I think many of my friends think that I am, for them." (Ceri, 29)*

Additionally, following social rules associated with non-autistic social behaviour involved the participants masking what they felt were their more authentically autistic social behaviours.

Most described how the (1) continual monitoring of performing emotional states through widely expected verbal and non-verbal communication styles, (2) taking part in small talk, and (3) avoiding stimming, all contributed towards exhaustion and feelings of overwhelm.

> *“It feels like, when you’re with other people, there’s something that’s always restricted and always a bit like you’re holding yourself in. I’m sure it has a lot to do with the fact that you’re constantly observing yourself being weird with other people. And monitoring the level of weirdness you’ve allowed yourself to get to and then holding that back to a certain extent.” (Flavia, 57)*
>
> *“There are habits I only feel comfortable with showing when I’m by myself. I mean that I get self-conscious stimming in front of other people but I feel overwhelmed when I have to consciously avoid stimming.” (Tom, 18)*

Many talked about the need to perform ‘switched on’ and ‘engaged’ for other people, even when they were distracted or tired from managing multiple social and sensory inputs. Extended periods with social and sensory distractions caused communication to become more difficult. Processing other people’s verbal communication and then trying to formulate verbal responses became particularly taxing. Sensory triggers such as background noise made focussing on communication harder; sensory and social input compounded difficulties, causing some to find themselves unable to speak. Pushing through communication difficulties to be polite and appear engaged caused further overwhelm.

> *“It is very tiring and if it’s extreme, I can end up becoming mute. I can’t process any more enough to reply, or ask questions or engage in any way.” (Jae, 58)*
>
> *“I’ve been told that in situations where I haven’t been able to be alone for a while, I’ve started giving people responses that are only one or two words each which sometimes gives the impression that I’m annoyed by other people. I now try to make sure that being overwhelmed doesn’t make me seem rude by being as polite as possible when I feel that way. This usually makes me feel even more overwhelmed though.” (Tom, 18)*

Whether at home or in work, many participants reported how social distractions (such as others talking to them or holding conversations around them) and sensory distractions (such as noises from electrical equipment or visual clutter in a space) made it difficult to think clearly or focus on completing tasks. This caused frustration, and also feeling isolated; people around them who were less distracted by social or sensory input didn't understand or appreciate the effort it took to try and block out these distractions and continue with whatever they were trying to do or think about. For example, one participant was briefly interrupted by a family member during our interview, and it took several minutes before she was able to collect her thoughts and return to our conversation.

> *"My brain is always working, always busy, always thinking, overthinking a lot of the time. And if it's not my thoughts its other people's thoughts in the house or other conversations that are going on. And it's just like I need there to be less sensory input reaching my brain because I'm dealing with everything that's going on in my head and dealing with external input. It can become overwhelming."* (Carys, 51)

> *"It transpires that I'm the only person that can hear all the fans and electrical equipment. So, I can never have quiet in that office environment because I can hear the fans and people's little individual tablets, I can hear the fans in the CCTV, and I can hear the fans in the big wireless router box that we've got at the other side of the room. And when I've kind of mentioned this to people over the past year or so, it doesn't register with anybody else, nobody else can hear it."* (Bill, 47)

> *"I can't concentrate if there's any distractions going on, like any noises. And then if I'm interrupted I find it difficult to get back and it takes time to get back into something."* (Susan, 61)

Ultimately, overwhelm reduced energy for self-care and being able to recover easily from experiencing difficult or intense social and sensory environments. By the time some of the participants were able to access spaces without social and sensory distractions and triggers, even the most basic life-skills already felt out of reach. There was sometimes a sense of having completed an endurance test by being away from home in social spaces, and of having nothing left to give at the end of it. For some, these times had to be planned in advance with clear and detailed written checklists for when they got home such as locking the door, eating and resting.

> *"Sometimes I get home and I'm like: I can't think, I don't know what I'm doing, I don't know what stuff is. And it's like: yeah you were around people too long."* (Emily, 27)

> *"I don't have the mental energy to do sensible things like eat the kind of foods that make me feel better, and having the vague energy to put out the bins."* (Ceri, 29)

This first theme identifies how social and related sensory input can be distracting and, eventually, overwhelming. Previous research has focussed on negative experiences of *either* social *or* sensory environments (e.g. Millington & Simmons, 2023; Verhulst, 2022; MacLennan *et al*., 2021; Belek, 2019), but here, these experiences were shown to be related in how they contributed towards overwhelm, and how overwhelm was experienced. Sensory agnosia, being flooded with sensory stimulation above the rate at which it can be processed, can result in fear, confusion and loss of verbal processing (Bogdashina, 2016). This experience was described by many of the participants. Sensory agnosia appeared to be preceded by strong feelings of agitation and frustration in the participants, a sequence which doesn't appear to be recognised in the literature. Research is needed to understand whether irritability is a precursor to meltdown for autistic people, as recognising warning signs to meltdown or shutdown experiences (crisis experiences which result in explosive or withdrawal behaviours) could help reduce frequency and severity. This is particularly important given that many autistic people find it difficult to recognise burnout symptoms until it is too late (Mantzalas *et al*., 2022a).

Autistic people's accounts of meltdowns and shutdowns, and how they contribute towards feelings of exhaustion, shame and failure, are frequently discussed in blogs and social media posts but are rarely reflected in the literature. Rather, observational research in the dominant autism literature focusses on reducing any resulting irritable, aggressive and withdrawal behaviours through medication or behavioural training. When academic and professional discourses view differences in social and sensory input experiences as maladaptive or disordered, then praxis is dominated by motivation to change how a person expresses overwhelm, rather than making environmental adaptions that would reduce that same overwhelm. However, more recent research which seeks to understand and explain autistic experiences has found that multiple factors including anxiety, sensory processing difficulties and social demands contribute to crisis states through overwhelm (Welch *et al*., 2021).

Many of my participants discussed anxiety and fatigue as consequences of behaving and communicating in non-autistic ways for the benefit of people who are not autistic, such as making eye contact, taking part in small talk and not stimming. These findings are mirrored in research into autistic masking or camouflaging (Cook *et al*., 2023; Bradley *et al*., 2021; Cook *et al*., 2021). Additionally, several participants mentioned that socialising with other neurodivergent people was generally easier and less stressful. However, with the exception of certain social activities (such as those which took place side-by side and/or were not based on verbal communication), many appeared to find *all* social interaction tiring and anxious-making. Particular difficulties with social interactions resulted from (1) processing multiple sensory and social inputs, (2) playing different roles for different interactions and (3) not feeling able to regulate sensory reactions to social and sensory inputs through stimming.

While overwhelm is rarely explored in the literature, recent studies seeking to explore and define autistic burnout relate closely to the current study. The temporary feelings of social and sensory overwhelm, as described by the participants, mirror long-term autistic burnout characteristics defined by Raymaker *et al*. (2020) as chronic exhaustion, loss of skills and reduced tolerance to stimuli. Autistic burnout, defined as lasting at least three months (Raymaker *et al.,* 2020), differentiates from mainstream descriptions of burnout in that social interaction, masking and sensory stressors contribute towards the onset of autistic burnout (Higgins *et al.,* 2021; Mantzalas *et al*. 2021). As such, social and sensory overwhelm should both be considered precursors to autistic burnout. Mantzalas *et al*. (2021) identify the benefits of social and sensory avoidance in recovery from autistic burnout, which mirrors this study's second theme.

4.2 Retreating from social and sensory overwhelm

Frequent or regular time spent alone, away from social input and negative sensory triggers was seen as a necessity rather than a luxury.

> *"I think it's vital. I couldn't function without it. It's a necessary part of me."* (Daisy, 47)
>
> *"I think it's an essential part of my being. I don't even think its a choice to have time alone."* (Flavia, 57)

It was really important for the participants to have spaces they could retreat to, generally rooms at home, with environments moderated to suit their own sensory needs, or in natural spaces where the types of sensory input were felt to be positive. However, a bathroom or a car could provide a temporary breathing space in an emergency, and sometimes social spaces could be adapted to feel more comfortable. What these spaces had in common was their potential to provide a safe space: a sanctuary or a refuge from overwhelming social and sensory input; a place to give both mind and body a necessary break, and a place where the sensory environment was felt to be soothing and supportive.

> *"I have two metres by two metres all to myself, this is my breathing space. Nobody's going to come and visit me because they think I'm weight training, and I sort of am, but only for five minutes, the rest of the time, that's for me… Let's have this space. Nobody's looking at me, nobody really minds what I'm getting up to. This feels lovely."* (Ceri, 29)
>
> *"It's vital that I just get that space. It's quiet, it's me alone, again its nobody talking to me and it gives me the headspace to process the day. I can do that and it just, it brings, I don't get the chance to finish thoughts at length if I'm not alone. I don't get processing time."* (Kirsty, 44)
>
> *"It's just like I need there to be less sensory input reaching my brain because I'm dealing with everything that's going on in my head and dealing with external input. It can become overwhelming. You can cope with it for so long and then you just need to extract yourself from the situation in order to just be more still, mentally."* (Cary's, 51)

Participants living with families, partners or flatmates described how a lockable bedroom, garage or converted shed could become an important sanctuary: a space where they would not be interrupted. Those who lived alone described the relief of shutting and locking their front door with the intention of ignoring anyone who might drop by, or turning their phone ringers off in order to retreat from the social world. Participants were clear that they put such measures in place to prevent the possibility of being disturbed before they had had the chance to rest and build up defences against another round of social input.

> *"I'm very happy, particularly of a winters evening - or summer, you can choose - just shutting the door."* (John, 48)

> *"If I'm on my own and the front door is shut I'm perfectly happy and relaxed."* (Flavia, 57)

> *"Something that I still do is just silencing my phone. I usually have it on vibrating mode but I just silence it. I don't pick up any calls."* (Cody, 20)

The environmental requirements of these safe spaces were often highly individualised, with participants putting in a great deal of energy to ensure that these spaces were adapted to their needs. Five key requirements, with varying levels of overlap, included (1) clear, minimalist spaces, (2) spaces where the temperature, light, sounds and smells were carefully moderated, (3) spaces that felt cosy, (4) visually interesting spaces, (5) spaces that felt safe and (6) spaces that were set up to accommodate any special interests.

> *"I prefer to keep it clean and not cluttery. I don't like having a lot of things around because it stresses me out. If I have a mess I have a feeling I have to fix it. And I have to clean this space and then that's also tiring so it's not exactly resting then."* (Cody, 20)

> *"This entire room was white and my whole house was white… But when I painted this room I came into see if it was dry. All of a sudden, I just like cried because I hadn't realised that the white was stressing me out and I realised I was so calm and I was like – oh my god what is this? And I just hadn't realised how stressed it was making me."* (Emily, 27)

> *"Most of the rooms aren't square so they have interesting angles and the doors are at an angle across the room. And there's an angle at the roof where the ceiling comes down and there's a lot of interesting little corners and they catch the light differently and you get wonderful patterns of light and shade. With the light coming through the blinds as well, it's just interesting."* (Sarah, 47)

> *"I designed the kitchen the way it is, it's for me. I don't want - oh your cupboards are too high - well they're exactly the right height for me. They weren't designed for you in mind. They're designed for me."* (John, 48)

Despite the individual requirements of these spaces, familiarity was also important, with no jarring surprises or sensory distractions that required effort to process.

> *"I like being alone at home, which is lovely because it's my space and I know where things are, I know what the noises are. One of the things I do to sort of take myself down a bit if I know I need some time away from the screen at work, and the house is empty, I will sit and I will do my noise identification, which is just – that's the traffic, that's the cats snoring, that's the fridge having a chat to me, that's the neighbours – and it's that quiet and being able to know what everything is that is happening and being in the quiet that's really important."* (Kirsty, 44)

A few participants noted that it wasn't always necessary to create or find a designated space to be alone in, sometimes small changes to the immediate environment was all that was needed to feel more comfortable and reduce overwhelm, such as earplugs, a change of clothes, or having the tools to hand that were necessary to lose oneself in a special interest.

> *"One thing that helps me feel more comfortable alone is the type of clothes I wear. I feel much more comfortable in pyjamas or loose clothes than I feel in the regular type of clothes I'd wear around other people… The clothes I wear are an important part of my environment and wearing the right clothes makes my environment much more comfortable for me."* (Tom, 18)

> *"It's a family joke, I make every space my space... But we only have a small family so I just bring my stuff with me wherever I go. I sew, I draw, I stitch, my stuff just goes everywhere with me."* (Maria, 53)

Most of the participants also reported retreating to natural spaces and gave detailed descriptions of how the sensory input from nature enhanced feelings of calm and safety. While some spoke of walking or sitting in their gardens or local green spaces as often as they could, a few reported going for solo hikes that could last days or even months, some would visit quiet beaches, and one described the peace experienced when solo diving. There was often a worry that other visitors to these spaces might try to start a conversation and some participants reported being resigned to the pressure to perform being friendly and engaged with those that might expect a response, and hence, reduce or delay the benefits of these spaces. Participants described how the experience of accessing natural spaces completely alone was different from being with others in terms of not feeling inhibited and being able to think clearly.

> *"I've always done things like, you know, gone off into the mountains with a tent, and I've spent a few days walking out in wide open spaces but by myself, actually enjoying getting away from people and by myself to kind of, I find it quite liberating really, kind of recharge and gather your thoughts about things and return refreshed."* (Bill, 47)

> *"The moors in winter are really clear, it's interesting weather-wise, you could get a lot of wind, be hard to hear yourself talk sometimes if you're up there. Sometimes you get deep snow. So, it's a real sort of treat for the senses. And I guess kind of a holiday for the senses if you want to put it that way."* (Jack, 40)

> *The way my mind works when I'm out on my own, walking, is one of my favourite things. It just flows and the systemising which I do constantly stops being a burden and becomes something that is nice and fun to do."* (Kirsty, 44)

Those that found it difficult to access solitary indoor or outdoor spaces, instead created temporary planned boundaries between themselves and others. Some planned for daily or weekly access to time alone, by asking household members to leave the house for a while, by putting out visual cues asking not to be disturbed, or by going on errands in order to leave a home or workspace for a bit.

> *"We have egg timers in our house, one for each of the times. And it's a visual thing, I just need 5 minutes, or 10, or 30 minutes. It goes on the bookcase or between our desks, it's a kind of, I just can't do anything, don't ask anything of me at this point in time."* (Ceri, 29)

During the interviews, some participants realised how often they planned excuses in advance of social events or group holidays, so that they would have an excuse to leave early or withdraw for a time.

> *"At parties I've always driven knowing that I would then likely drive in case I just wanted to leave. Driving a car was always my get out clause, it was always the option I had. To get away from somewhere I didn't enjoy being."* (John, 48)

For several participants, waking up early in a busy household, or going to bed after everyone else, was the only way to ensure time alone in a quiet space, even though it meant missing out on sleep.

> *"I get up super early so that I can have ideally three hours in the morning by myself."* (Flavia, 57)
>
> *"I used to sneak out and go on the swings at like one in the morning. I'd just sneak out the house and go across the street to the park and go on the swings. Because I just needed like the dark and the rhythm of it and the quiet… And I would get up before everyone else and do whatever I needed to do and then by the time they were up I was in my room. But I was very sleep deprived."* (Emily, 27)
>
> *"But let's say that they're getting up at nine and so I get up at six to just, you know have two or three hours by myself, and spend time with my pets."* (Cody, 20)
>
> *"I went on holiday with some friends of mine… they'd go to the pub in the evening and I'd last about an hour and leave the pub at eight and just spend the evening on my own and just wake up like four hours before them every morning and have that time on my own. And it was such a good holiday."* (Jack, 44)

Many participants referred to a need to escape when things became too much, and described the places that didn't cause further social or sensory overwhelm as 'safe' and providing 'sanctuary'. The need for autistic adults to be able to retreat from social and sensory overwhelm is rarely discussed in the literature. However, Quadt *et al*. (2021) note that needing solitude and low-arousal environments at least partially arises from the overwhelm experienced during social encounters, and MacLennan *et al*. (2022) highlight how designated recovery spaces are needed in public spaces for autistic people experiencing overwhelm. Having a safe, uninterruptable space may have become a bit of a cliché in modern times, with 'mancave' and 'she-shed' becoming commonly used terms for places of solitude and refuge within shared, and thus 'contested-space' homes, particularly during the Covid-19 lockdowns (Shortt, 2021); however, these spaces can be vital.

Meanwhile, 'escape behaviour' is commonly referred to as 'elopement' in autistic children in the context of behavioural interventions designed to stop autistic children running away from public spaces. These interventions include physically blocking the child's escape, taking favourite items away from them, and continually returning them to the area they had run away from until they no longer run away (e.g. Scheithauer *et al*., 2021; Boyle *et al*., 2019; Call *et al*., 2017). Given the descriptions of overwhelm and the need for retreat given by the autistic adults in the current study, it is perhaps surprising that interventions do not first seek to understand an autistic person's reasons for bolting from any particular environment in the first place. Creating designated spaces for overwhelmed autistic people of all ages would seem a far kinder, more effective and enabling intervention than blocking 'elopement.'

While links between mental health and wellbeing with access to natural spaces are well documented, very little research has been carried out specifically with autistic adults. One exception is a study showing that nature provided stress relief for autistic adults during Covid-19 lockdowns through physical distance from others, feeling connected to nature, and also feeling more connected to others (Friedman *et al*., 2023). However, the experiences that participants from the current study described from being in natural spaces are mirrored in a study by Brymer *et al*. (2021) with adult participants from the general population. This study found that natural spaces provide "*space for processing, a sanctuary from stressors and, at the same time acceptance and non-judgement."* (p. 402). Additionally, Brymer's *et al*. participants felt able to just 'be' without feeling judged; which gave them the freedom to switch off from current concerns and feel immersed in the sensory environment. These findings link to masking or camouflaging (discussed in Theme 1) and immersion (to be discussed in Theme 3), showing that these concepts are not unique to autistic people. However, higher rates of mental health challenges such as anxiety and depression suggest that autistic people may have more of a need for the mental and emotional sanctuary offered by natural spaces.

4.3 Regulating, recovering and recharging

In response to social and sensory overwhelm (Theme 1), retreating to a safe and healing environment (Theme 2) was one method of regulating overwhelm, but another, more active strategy, which might take place after a period of retreat or be used as a stand-alone strategy, related to immersion within an activity, which several participants described as being in flow-state. Theme 3 describes how participants used some of their time alone to recover and recharge their batteries through being immersed in an activity.

> *"It's kind of a recharge, and then it becomes an active recharge. It's a multistage process. I just realised, the more I talk about it the more I see there are rituals to it that I had not realised."* (Ceri, 29)
>
> *"Oh god yeah its lovely [focussing on an intense interest]. Absolutely lovely. The time passes. I don't worry about anything and I'm doing something I find absolutely fascinating… I come out of it calmer. Calmer, more relaxed, more serene, and more resilient."* (Kirsty, 44)
>
> *"It's actually a nice feeling being in the flow-state. Everything flows. It just feels nicer. No effort. I can feel the difference in my body. It's smooth. It feels healthier."* (Jae, 58)

In particular, most talked about fully immersing themselves in a special interest such as making music, researching, gardening or bike maintenance. This immersion bought joy, and also the opportunity to process thoughts and emotions that had built up during the day or, conversely, an opportunity to dissociate from them. Processing or dissociating from thoughts and emotions through being immersed in an activity both had the effect of alleviating anxiety, worry and perseverant thoughts.

> *"It's just me. I'll pick up a guitar and have a sing along. Just for my own amusement. And to get the voice out. Not to impress anybody, just to sing. Just to express."* (Lori, 53)
>
> *"I've realized that I do have to be doing something. I can't just sit and do nothing. I used to meditate but not anymore. I suspect that the always doing something is about occupying my mind so that I'm not overthinking, catastrophising, or going over stuff again and again."* (Jae, 58)
>
> *"But there's always been a certain sort of therapeutic quality to either being by yourself, of being completely absorbed in whatever interests you have at the time really."* (Bill, 47)

In flow-state, even activities that others might find stressful, like commuting, gaming and learning a new skill set were felt to be relaxing.

> *"You just really have to focus on what you're feeling [when motorbiking], like through your body, the feeling of the road and what you're seeing and hearing around you and constantly processing that in an ongoing flow... And it's relaxing... kind of like the flow states that people have written about… I don't have to project an emotional state and I don't have to think about things or worry about anything else other than the physics of it, like the traction of the road and the relative speed of other vehicles."* (Jack, 40)

> *"Video games are, I guess, similar. I tend to be drawn to things that are quite challenging. I guess it's kind of the same, you develop the same kind of skill set and respond to visual and audio cues and you can just kind of let the sort of social and emotional aspect of your thinking and a lot of the complex thinking of that kind of drop away."* (Jack, 40)

> *"So other people might think that sitting at a computer, you know, doing research or whatever is not relaxing, but to me it was yeah, well it is. I think it's how my mind relaxes."* (Susan, 61)

While some immersion or flow-state activities required as little sensory input as possible in order to focus on the activity itself, some activities revolved around being immersed in sensory aspects of the external world. This immersion was often enhanced by or centred around recording sensory details. Photographing, sound recording and writing was not generally for public consumption but rather for the enjoyment of recording and editing these details or candid shots. Several participants enjoyed taking close-up photographs of plants or similar details which caught their eye, documenting seasonal changes on film, or recording sounds, while others preferred not to document it.

> *"I love walking through woodland, I love the way the light falls through the trees… there's the motion but also the complexity of the patterns and the way that the light changes as you're walking through that sort of dappled filtering of the sunlight. When you've got that little hint of haze in the air where you can actually see the rays and its, ohh! And water as well, sunlight off water, I can just sit and watch it. I find it captivating. I get excited about it and when I don't have people around me I don't feel inhibited about that… If I want to start jumping up and down and pointing at*

> *something and giggling, I can do it and I can just enjoy the moment in any way I like."* (Sarah, 47)
>
> *"You'd see stuff like bats, barn owls flying over and all kinds of things, larks, skylarks ascending and descending and you know you're right just in the middle of it. It's wonderful."* (Lori, 53)
>
> *"I love taking photographs. And those photographs, and sort of slow-mos keep me going for ages afterwards. So, I take slow-mo shots of the sea. And audio of the sea coming and going. And the sound. Because it's a very loud silence at the seaside. It just removes, it filters out the internal noises that we all have."* (Maria, 53)

Three participants described a passion for street photography, taking photos of people, architecture and street art. Although street photography took place in busy urban spaces, there was no obligation to interact with other people; focusing on the camera provided protection and distraction from other social and sensory inputs meaning that they felt less uncomfortable in these social environments than without a camera.

> *"Flaky paint on door-handles, and milk-bottles being put out and, just personal things that, even clothes on washing lines, which I probably shouldn't have taken photos of, but building up a collection of that became a process of the rhythm of walking and the close observation [which has] the same effect on me as sitting and zoning out."* (Daisy, 47)
>
> *I have a particular thing about street art and I like photographing it and wandering around taking photographs of architecture, structures, patterns, details of things… I take an awful lot of photos of things that other people might think – why on earth are you taking photos off that? But it pleases me. I get enormous satisfaction.* (Carys, 51)

Immersion in fictional worlds was enjoyable for most of the participants. Many could lose themselves for hours reading fiction, and enjoyed reading favourite books multiple times, with one participant reporting that the books she'd read "*7, 8, 9 times*" (Emily, 27) were her comfort books. Similarly, some reported that watching films or televised series multiple times helped to relieve stress. These fictional worlds often felt safer, easier and more comfortably predictable than real-world environments.

> *"I could get the same amount of joy from reading something the fifth or sixth time as the first time around. Even though I can remember the phrases and the plot. You can lose yourself in the details, these are safe environments for you, even if they are unsafe, you know what's happening and you can get absorbed in a world. It feels really lovely. It's a joy."* (Ceri, 29)
>
> *"Watching TV is a great way to distract myself after I've already been in a space that was overwhelming to me. TV helps me to avoid thinking about overwhelming and stressful situations for long enough that they stop making me feel as stressed out or overwhelming as they were before."* (Tom, 18)

The benefits of immersion in a preferred activity have only recently been explored in the autism literature, but evidence points towards an association between time spent engaging with preferred or intense interests, and increased wellbeing. Autistic people are widely acknowledged to have intense interests, described by the DSM-5 in pathological terminology as "*highly restricted, fixated interests that are abnormal in intensity or focus*" (American Psychiatric Association, 2013); referred to by the general population using stigmatising terms such as 'train spotters,' 'trekkies' or 'nerds'; but viewed positively within the autistic community, with many online global interest groups set up to discuss areas of intense interests without fear of stigma. As such, immersion can also be considered in terms of autistic sociality, described by Beardon (2023) as one's autistic social perspective, needs and wishes, in that immersion can also be a social experience. In terms of wellbeing, social immersion will likely equal social activities not based around immersion. While social immersion merits further research, it is outside the scope of this thesis which focuses on alone-time.

Alongside a need for space to recover and replenish energy, Higgins *et al.* (2021) and Mantzalas *et al*. (2022a), found that time spent on intense interests was a recovery strategy for autistic burnout through sensory and emotion regulation. Additionally, this time is considered to provide background maintenance, contributing towards long-term wellbeing (Mantzalas *et al*., 2022a). Not only does exhaustion from autistic burnout often prevent engagement with intense interests; the inability to access the benefits of this time causes further distress (Mantzalas *et al.* 2022a). This suggests that the current study's second theme, *retreating from social and sensory distraction*, may often provide a necessary bridge between more extreme experiences of overwhelm or burnout, and *regulating, recovering and recharging* through engaging with intense interests.

Engaging with intense (also referred to in autistic and autism communities as special or preferred) interests is viewed by autistic adults as a positive and calming experience which leads to a decrease in overall anxiety (Koenig *et al*., 2017); and a study with autistic children and young people found that doing preferred activities was helpful in regaining control over negative thoughts, physical reactions and emotions (Phung *et al*., 2021). Pavlopoulou's *et al*. (2020) research with autistic adolescents found that engagement with highly preferred items and activities, such as writing, making music, gaming and watching favourite movies during the day helped them reach a state of calm happiness that ultimately helped them to sleep better at night. It would be interesting to know if this was also the case with autistic adults.

As discussed in Chapter Two, many autistic people are considered to be sensory-seeking, drawn to or fascinated by visual, auditory, tactile, gustatory or vestibular sensory experiences for enjoyment and/or emotional regulation (MacLennan et al., 2022a; Bogdashina, 2016). Although many of the participants discussed the enjoyment of immersion in sensory experience, this is rarely referred to in the literature. However, Conn's (2015) paper on autistic adult's autobiographical descriptions of their childhood play found that while many engaged in social play, the largest amount of writing centred around the enjoyment of sensory experience, whether passive (audio, visual, tactile etc.) or active (swinging, twirling, hanging upside down etc.). This sensory regulation links to stim practices (see Chapter Two) which, although also used in the general population, are extensively used by many autistic people to reduce negative physical or emotional discomfort and increase feelings of wellbeing (Felepchuck, 2021; Charlton *et al*., 2021; Kapp *et al*., 2019).

It is interesting to note that, for several of my participants, engaging with technology (including gaming and data inputting) was discussed as being relaxing. While gaming is often acknowledged to have detrimental effects to wellbeing, many autistic young people use technology to distract themselves, relax and add joy to their day (Cheak-Zamora & Odunleye, 2022). Additionally, online gaming fosters a sense of autonomy and belonging, increases feelings of positivity and joy, and provides an opportunity to release negative emotion for autistic adolescent boys (Pavlopoulou *et al*., 2022).

4.4 Ready to reconnect with others

Ultimately, spending time with others was desirable for most of the participants, but without access to time alone through safe-spaces or flow-state activities, both before and after sociable activities (including work environments and time spent with family), being sociable was a source of stress rather than enjoyment.

> *"It's not that I don't like people, because I like people, to spend time with people. But only if I'm well enough and rested, prepared and have time after this." (Cody, 20)*

Some of the participants considered themselves to be sociable people, describing how much they liked being with other people and how much they needed regular contact with others for their wellbeing, but still how they needed frequent time away from people. The balancing act between time with others and time alone was something that many had noticed since they were young, but felt conflicted about it until they were aware of their autistic identity and found this need reflected in other autistic people.

In particular, while lockdown during the Covid-19 pandemic was assumed by many to be easier on autistic people, working at home had often been very difficult for those who lived alone and were used to sharing work-spaces with others. They often felt a conflict between the relief of not having sensory and social distractions at work, and struggling with the experience of loneliness. Meanwhile, those that were used to working at home and/or having a portion of the day at home without social distractions, and who then had partners or family members at home with them, experienced difficulty with focus and pressure to mask more frequently throughout the day. Both groups lost the autonomy to balance time with others and time alone.

> *"I think I didn't really realise how much of a need it was to have time around at least somebody else until that first lockdown really hit and with anxiety I just couldn't go out to the store or anything. I was stuck in here and I've been struggling with mental health anyway but this just really, completely drove me up the wall, round the bend, whatever the phrase. Yeah, I kind of ended up in a crisis because of it."* (Sarah, 47)

> *"I think that it was – oh he's got this thing* [autism] *so he'll be alright working at home by himself. But actually, coming out the other end of that I'm being home by myself all the time I'm really struggling with it."* (Bill, 47)

> *"I was so used to having the house to myself from eight to six and then I was coming down for a coffee in the middle of the day. He'd speak to me and I was just horrified [laughs]… And I was absolutely hyper-focused and immersed and I'd come down and he'd say something to me, perfectly ordinary like – I think I might pop to the shop – and it would drag me out of my hyper-focus and I'd get so cross!"* (Kirsty, 44)

Much as with retreating and recovering from overwhelm, quiet time alone in suitable environments, was felt to be beneficial in preparing for socialising. It was important to feel rested and calm, rather than going into a social situation with no energy reserves, and it was also important to know that there would be a chance to rest again afterwards.

> *"I need things to wind down so that there's enough space to wind them up again if I'm around people again."* (Emily, 27)

> *"But if I've been in the countryside for a while, like when I was three months out walking in the countryside, then I was much, much more able to deal with people. I even stayed at youth hostels and stuff and was able to have conversations with people and feel a lot more relaxed."* (Flavia, 57)

Some participants also talked about feeling guilty for not seeing friends and family more often, or for not having the energy or focus to engage fully when they did meet. Rather than let people down they had developed systems or timetables that alternated socialising with time alone to ensure they could fully participate in seeing friends and family on some days of the week, or at certain times of the day without feeling too overwhelmed.

> "I *enjoy it so much more when I get all the space I need. I feel like the quality is better. I feel less heavy, less rushed, and less - let's just hurry and get this over and done with… Otherwise you feel really guilty if you don't get to enjoy it. Whereas, if I've had that time, I can look forward to it then."* (Ceri, 29)

> *"Every week, I see friends on Tuesdays and Thursdays. I also spend time with my family on Wednesdays. I have particular times that I start seeing people on those days too. I spend time with my family starting at dinner at six pm and I see my friends*

> *at four pm. I spend time with people on other days than just those three but it makes it easier for me to say when I'm not feeling up to being around people if we all know that we've spent time together within a week. It's also just less overwhelming doing something when it's part of my routine."* (Tom, 18)

Social events that were desirable and enjoyable tended to be (1) within small groups, (2) based around a shared interest, and/or (3) with other neurodivergent people. Many talked about large social groups as being overwhelming and something to either endure or escape from. However, small groups or one-on-one interactions were often preferred.

> *"There's often a question going 'round Twitter - if you could have five people round to dinner who you would you choose? I'd hate it. Can't I just have two? Just give me two, you know?" (John, 48)*

> *"I certainly don't want fifteen people talking to me at the same time. I'm more than happy to have one-to-one of really good, quality interactions with somebody, some other person sitting next to me." (Maria, 53)*

> *"I find it overwhelming being around a lot of people when they're being loud or when a lot of people are talking to me. I'm fine when it's quiet and when I only have to interact with a couple of people." (Tom, 18)*

Shared interests could mean that socialising was based around a shared activity such as walking, making music, crafting or watching films. This relieved the pressure to focus on masking through non-autistic social behaviours and styles of communication.

> *"Watching tv shows and films is a nice way for me to be around my friends and family without taking up as much energy as usual. If I watch tv with my family or go to the cinema with my friends, I have something other than them that I can focus on without being rude. I feel least overwhelmed spending time with people when we're seeing things that I can get distracted by." (Tom, 18)*

> *"We could have all three of us all sitting in the same room and we're all sitting on our phones doing our own thing and that's fine." (Carys, 51)*

Meanwhile, two of the participants talked of group socialising being focussed around shared interests and experiences in more spiritual terms:

> *"When I was young enough to have other people around that were also musicians I used to find that really almost spiritual. Such a very strong bond, sometimes it meant a lot to me... Doing that together, even just rehearsing or jamming or whatever, it was always really special."* (Lori, 53)

> *"To me it's something close to collective worship because you're all there enjoying the same quasi spiritual experience because its feeding your soul and you're all experiencing this same thing. And I'm not particularly one to put myself into crowd situations but there's something slightly different about the dynamic of an audience all listening to music where you're all having a shared experience."* (Carys, 51)

Some talked about how shared-interest activities were likely to attract other neurodivergent people, which made socialising easier. With other neurodivergent people, there was less pressure to adopt non-autistic social behaviours and communication and more understanding of sensory sensitivities, ultimately resulting in less social and sensory overwhelm.

> *"Any friend I've felt a connection to over my life, any person I've felt easy with, has always turned out to be autistic or in some way neurodivergent. I think that the trick is to find the interest and then follow the interest to a community of people because you'll quite often get an autistic person in that community of people."* (Kirsty, 44)

> *"So, the reason that I go [to eco-therapy] is to get better at being around people again, and more confident in talking to people. Because there's something we're actually doing you've got something to focus on. And talk about."* (Emily, 27)

> *"I've built up quite a network of autistic people… and we can have fun and silly conversations – very autistic in humour and topics. I find them very comforting."* (Jae, 58)

Despite social input often being overwhelming and exhausting for the participants, it was apparent that many still needed and welcomed social interaction, and felt isolated when they were not physically or emotionally able to connect with other people. Autistic people have a need for periods of solitude but also have significantly higher levels of loneliness and loneliness distress than people who are not autistic (Quadt *et al.*, 2021), which can lead to feelings of isolation, anxiety and depression (Milton & Sims, 2016). Loneliness can also arise from living as an ‘othered’ member of society (Botha, 2020; Milton & Sims, 2016). However, shared interests, experiences and understanding with other autistic people create a sense of wellbeing, belonging and resilience as well as feeling able to be one’s authentic self (Cook *et al*., 2023; Keates, 2023; Crompton *et al*., 2020a; Milton & Sims, 2016). In particular, the benefits of autistic community connectedness include *“increased self-esteem, a sense of direction and a sense of community not experienced elsewhere”* (Botha et al., 2022, p.1). This suggests that a key benefit of self-identification, professional assessment or clinical diagnosis of autism is to help enable access to autistic communities, and foster a sense of belonging.

Preferring to socialise in small groups may relate to the increased social and sensory input which arises from communication and sensory aspects of larger groups. Many autistic people find that background noise, visual input and concurrent conversations are difficult to process (Black *et al*., 2023; Parmer *et al*., 2021; Landon *et al*. 2016), ultimately causing overwhelm. People who are not autistic can reduce the burden of social and sensory input which are challenging for autistic people by asking what can help, understanding and accepting differences in processing, and respecting needs for socialising in preferred environments (Cook *et al*., 2023). For instance, the shared experiences that my participants described, such as attending concerts, watching TV or going to the cinema, reduce the burden of processing and responding to direct communication, while also reducing the need to mask authentically autistic behaviours such as communication styles and stimming.

4.5 Discussion

In the introduction to this chapter I explained why my thematic map did not have a circular flow. Although social and sensory environments often cause overwhelm (Theme 1), it does not follow that *all* social and sensory environments cause overwhelm. If retreating (Theme 2), regulating (Theme 3) and reconnecting (Theme 4) are balanced according to individual needs and desires, then overwhelm, a pervasive aspect of many autistic people’s lives, becomes easier to avoid. However, with so little public understanding of the social and sensory overwhelm experienced by autistic people, let alone why and how autistic people need to balance time spent retreating and regulating with reconnecting, many autistic people, anecdotally at least, find it difficult to justify to themselves and others why each of these aspects is necessary for their wellbeing.

A note on the themes in relation to literature on autism and Covid-19

While the interviews took place after many of the Spring-Summer 2021 pandemic lockdown restrictions had been eased, many of the participants were currently impacted by changes in working from home or their partners working from home. The pandemic and restrictions were not a focus of the interviews although several participants referred to both positive and negative impacts of social restrictions. I analysed the data and identified the four themes before any literature on autistic mental health and wellbeing during lockdown was published, and so was not influenced by research into how autistic people experienced the Covid-19 lockdown restrictions. However, positive wellbeing factors identified in the recent Covid-19 lockdowns autism literature included reduced social masking and conventional social challenges , greater control over the sensory environment, increased connection with family, and more time to engage in special interests (Bundy *et al*., 2022; Pellicano *et al*., 2022; Heyworth *et al*., 2022) while negative factors included reduced social interactions, reduced community connection, and reduced opportunities to self-regulate through alone-time. (Bundy *et al*., 2022; Pellicano *et al*., 2022; Heyworth *et al*., 2022). Each of these findings was clearly reflected in my participants' interview data.

Chapter conclusions

I designed the first phase of my research to qualitatively answer the first two research questions: (1) To what extent do autistic adults choose to create regular time alone? and (2) How and where do they choose to spend this time? Reflexive TA enabled me to generate four key themes describing why autistic adults might choose to spend time alone, the different ways that autistic people choose to spend this time, and the different spaces that they choose to spend this time in. Time alone, in chosen environments and engaging in chosen activities appear to help autistic adults to recover and self-regulate after experiencing social and sensory overwhelm, and help them to 'recharge batteries' before re-entering the social world. This time alone might be spent resting and/or being immersed in an activity, and it might be spent indoors or outdoors - as long as there are no expectations of engaging with other people. As discussed in Chapter One, I expected participants to discuss the impact of not being able to access time alone in chosen spaces and with chosen activities, in terms of anxiety. However, although shutdown, meltdown and autistic burnout resulting from social and sensory overwhelm were discussed, participants were more likely to describe the wellbeing aspects of this time alone. The resulting shift away from anxiety and towards wellbeing will be discussed in the next chapter.

So far in this thesis, I have reviewed literature on aetiologic understandings of autism, and their impacts on autistic wellbeing; introduced my positionality as an autistic autism researcher using a pragmatic framing, described my mixed-methods exploratory sequential research design, outlined the qualitative methods, and presented and discussed the findings from the initial qualitative phase. In the next chapter I describe how the qualitative findings informed development of the quantitative phase, and then how the quantitative phase was designed, implemented and analysed.

Chapter Five: Methodology Part 2

> "An autistic person's weekend plans may *sound* uneventful, but many of us get joy from things that are less "showy" (like our special interests), and need our weekends to be calm so we can recover all the additional energy we give to our weekdays and give it all again next week."
>
> - *Callum Stephen (2022), autistic writer (via twitter).*

In line with exploratory sequential mixed methods research design, I used themes and codes from the initial qualitative phase to develop a quantitative questionnaire survey. As such, not only were the survey questions designed to reflect qualitative findings, but the aim of the study itself evolved as the original emphasis on anxiety changed to a new emphasis on wellbeing. Originally the combined phases were designed to answer three research questions with the aim of exploring how alone-time for autistic adults might be used to reduce anxiety. The initial phase focussed on my first two research questions:

RQ1: To what extent do autistic adults choose to create regular time alone?

RQ2: How and where do they choose to spend this time?

These were qualitatively answered within the four themes described in the previous chapter. The second phase used descriptive statistics to quantify RQ2 "How and where do they choose to spend this time?" and was, at the outset of my PhD, also designed to answer RQ3: "Is there an association between using this time and space, and self-reported anxiety levels?" As the participants in the qualitative phase did not discuss anxiety in the semi-structured interviews, but rather talked about overall wellbeing benefits to 'alone-time', the CAG recommended that the research focus should be changed from anxiety to wellbeing and suggested the Warwick Edinburgh Mental Well-Being Scale as a suitable measure. As such the third research question was rewritten:

RQ3: Is there an association between using this time and space, and self-reported wellbeing levels?

This chapter has two main sections. The first describes the development and data collection for the quantitative phase, and the second describes the statistical analysis methods used to quantitatively answer RQ2 and fully answer RQ3.

5.1 Development of the quantitative phase

A key feature of exploratory sequential research design is integration: using the qualitative results to inform the development of the quantitative feature, thus grounding the quantitative feature in the culture and perspectives of participants (Creswell & Plano Clark, 2018), and so I begin this chapter section with a discussion of the integration of methods before describing the more traditionally quantitative elements of the questionnaire development.

Developing the qualitative findings into the quantitative survey

Integration in a mixed-methods exploratory sequential design involves building a quantitative feature from the qualitative results; in this case collecting and analysing interview data and then designing a quantitative survey based on the qualitative findings. A key strength of the exploratory sequential design as used in the current study is that the integration of the qualitative and quantitative phases helped ensure that personal and cultural autistic experiences were embedded into the survey questions, making the survey culturally and contextually sensitive (Creswell & Plano Clark, 2018). I considered that this process was particularly important in (1) counteracting the dominant autism literature - which is embedded in deficit-based and observational understandings of autism, and (2) contributing to new understandings of how the social and sensory environment impact the autistic experience - in turn, this may inform future knowledge about autistic wellbeing.

Plano Clark and Ivankova's rationales for mixed methods research

Plano Clark and Ivankova (2016) describe five rationales for mixed methods research: offsetting strengths and weaknesses, triangulation, complementarity, development and social justice. In my thesis introduction I briefly outlined my own motivation for choosing a mixed methods study design, but here I refer to each of Plano Clark and Ivankova's rationales for describing how the quantitative phase was informed by the qualitative phase, and justifying my reasons for addressing the research aim in this way.

Offsetting strengths and weaknesses

Offsetting qualitative and quantitative strengths and weaknesses is often considered to provide stronger inferences (Teddlie & Tashakkori, 2009). However, Plano Clark and

Ivankova (2016) warn against using this rationale without being explicit about how these strengths and weaknesses are defined, and the assumptions that form the basis of these opinions. A purely qualitative study on how autistic adults use time alone to benefit their wellbeing would have provided rich, contextual descriptions but may have lacked generalisability across the adult autistic population in the UK. It was important to me that the qualitative data would not get lost or dismissed for only representing a small number of the autistic population. Meanwhile, a purely quantitative study with a large, representative sample may have produced generalisable results, showing how preferred spaces and activities were felt to contribute towards wellbeing, but would likely have lacked detail, nuance, and possibly also accuracy in reflecting autistic adults needs and experiences. Developing a set of quantitative survey items that were culturally relevant to the population being studied was necessary; a feature that is often overlooked in quantitative autism research.

Triangulation

Directly comparing results from qualitative methods and quantitative methods for convergence and divergence is often thought to obtain more valid conclusions about a phenomenon (Plano Clark & Ivankova, 2016); if the results agree, then a researcher can be confident about the validity of the findings; meanwhile, discrepancies can be reconciled or explored through further steps. However, Plano Clark and Ivankova also warn that qualitative and quantitative methods cannot always study the same phenomenon due to the methods’ differing philosophical assumptions. In this case, as I took a pragmatic approach throughout, there was no issue with differing philosophical assumptions. Rather, triangulation was hindered by the qualitative and quantitative phases answering different research questions; only RQ2 was designed to be answered both qualitatively and quantitatively. As such, being able to triangulate the qualitative and quantitative findings was less relevant for this study than for one with a set of research questions that needed to be answered both qualitatively and quantitatively.

Complementarity

While triangulation (above) is an argument for comparing and contrasting qualitative and quantitative results, complementarity aims to obtain more meaningful and complete conclusions by using the qualitative and quantitative results to get complementary results about different facets of a phenomenon (Plano Clark & Ivankova, 2016). In the current study, RQ1 and RQ3 were designed only to be answered by one method so as to examine different aspects of the research aim, while RQ2 was designed to gain both qualitative and quantitative findings about how and where autistic adults choose to spend time alone. Complimentary results were necessary to meet the aim of this PhD study, i.e. an exploration into how autistic adults use alone-time to improve wellbeing. Using different methods to answer different research questions supported this exploration of a previously under-researched phenomenon.

Development

Sequential mixed method designs allow an initial phase to inform the development of a second phase. Table 5.1 illustrates how the initial qualitative findings were used to culturally and contextually inform development of the quantitative questionnaire. This side-by-side joint display design was originally developed by Peterson *et al*. (2013) to show how participant values and beliefs, learned in an initial qualitative phase, were used to refine clinical interventions. Here I have used the display design to show how the qualitative findings and the post-qualitative phase insights of the community advisory group (CAG) were instrumental in the development of the questionnaire.

Table 5.1: Joint display describing how the qualitative findings informed the quantitative survey

Area	Methodology revisions	Cultural tailoring
Alone-time definition and respondent clarification	The definition of alone-time was undefined during the qualitative phase.	Qualitative findings were used to help (1) shape a tentative definition for using in the survey and (2) ask respondents to clarify what one of the qualifications of this description meant to them.
Preferred activities	The original proposal did not specify which activities would be included in the survey.	The lists and groups of activities were mostly derived from the qualitative findings.
Preferred environments	The original proposal did not specify which environments or environmental considerations would be included in the survey.	The lists and groups of environments were mostly derived from the qualitative findings. As most participants in the qualitative phase discussed both indoor and outdoor environments, the questionnaire was designed so that for participants could list their preferences for both environments.
Validated questionnaire measure	The original proposal specified the use of the 21-item Depression, Anxiety and Stress Scale measure.	As the qualitative data reflected a focus on wellbeing rather than anxiety, the 14-item Warwick-Edinburgh Mental Well-Being Scale was identified by a CAG member. The group agreed that this measure better reflected the participants experiences from the qualitative phase and considered that it was less pathologizing than other autism-specific validated measures.
Demographic questionnaire questions	Although the intent was always to keep demographic questions to a bare minimum, the original proposal did not specify which demographic items would be included.	Following qualitative findings, the CAG felt it was important to know more about the respondents. Various socio-economic scales were considered by the CAG. Household finances, employment and social backgrounds were considered very changeable states for autistic people. Educational attainment was felt to assess a more meaningful spread of participants.

Social justice rationale

The previous four rationales emphasize methodological considerations, but a social justice rationale is concerned with ideology and researcher values, as mixed methods research is ideally placed to involve and include marginalised people's voices (Plano Clark & Ivankova, 2016). For instance, in the current study, the survey questions on how and where autistic people spend their alone-time were based on interview data with autistic people, rather than assumptions. Another social justice argument for mixed methods could be that results that are viewed as credible to different stakeholder groups; community partners may trust qualitative findings featuring authentic voices more, while policy makers may place more trust in quantitative results (Plano Clark & Ivankova, 2016). As this research is intended to be used by autistic people as well as incorporated into societal structures, it is important that the findings are considered as credible by multiple stakeholder groups.

Defining alone-time

During the qualitative phase myself, the CAG, and the participants variously referred to time alone as alone-time, me-time and/or decompression-time without needing to commit to a term or definition; these informal terms are all commonly used and understood in autistic communities. However, during the development of the quantitative phase it became apparent that the term 'alone-time', as the most frequently used and commonly understood term, should be formally defined for the purposes of the survey. My personal understanding of alone-time requirements had gradually developed during the qualitative interviews into three conditions, which I discussed with the CAG, and were agreed as follows: 1) you are in a space where you aren't interrupted or distracted by other people, (2) you are in a space where you feel comfortable, and (3) you are able to choose what you do. These conditions were used in the questionnaires, and their usage, qualification and usefulness are discussed during this chapter and in Chapter Six.

Instrument development

Questionnaire surveys offer the ability to collect generalisable data in a standardised way; online survey tools such as Qualtrics are cost effective, are flexible in terms of design, can easily include participant information forms and consent statements, and allow for data to be exported directly into a statistical software package (Pilkington, 2020a).

A one-off questionnaire which includes a wellbeing measure can answer questions about a participant at a single point in time. However, I expected that (1) the amount of alone-time a person had, and the amount of alone-time a person might want, from one time point to another would differ, and (2) that the difference between time wanted and time experienced would be reflected in self-reported wellbeing levels at one or more time points. To look for associations between these two instances, questionnaires were delivered at two time points, two weeks apart, so that variables in individuals' first and second questionnaires could be compared (discussed later in this chapter section). Including additional time points (i.e. delivering a questionnaire at three or more time points) was considered but decided against so as to reduce the burden to respondents. As the questions (other than the wellbeing scale) were new, and thus not previously validated, a pre-test and pilot stage were included in the development of the questionnaire.

Please note that I use the terms 'respondent', 'test participant', and 'participant' for different purposes throughout this chapter and the remaining thesis chapters. I use 'respondents' to indicate those who took part in the final survey, submitting predominantly closed-ended responses; 'test participants' to indicate those who took part in the pilot survey and engaged with open ended questions to help develop the final survey; and 'participants' for those who took part in my qualitative study.

The two questionnaires were developed to quantitatively answer the following questions:

1. How do autistic adults choose to spend alone-time?
2. What alone-time activities are most important to autistic adults for their wellbeing?
3. Where do autistic adults choose to spend alone-time?
4. What alone-time environments are most important to autistic adults for their wellbeing?
5. Is there a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point?
6. Is there a relationship between this difference and wellbeing at the same time point?
7. Is there a relationship between the difference between alone-time wanted and alone-time had at time point 1 with the change in wellbeing at both time points?
8. Is there an association between the number of alone-time hours had at each time point, and wellbeing at the same time point?

9. Is there an association with wellbeing at time point 1 and the number of alone-time hours wanted at time point 2?

Questionnaire 1 asked respondents for their own understanding of the provided definition of alone-time as:

1. space where they wouldn't be interrupted or distracted by other people
2. space where they felt comfortable
3. time when they could choose what they did.

It then asked respondents:

1. how much daily alone-time they had *had* on average in the past two weeks
2. how much daily alone time they had *wanted* on average in the past two weeks
3. how and where they chose to spend their alone-time
4. what activities and spaces they felt to be most beneficial for wellbeing
5. their wellbeing over the past two weeks
6. demographic questions.

Questionnaire 2 repeated questions about:

1. how much daily alone-time they *had* on average in the past two weeks
2. how much daily alone-time they had *wanted* on average in the past two weeks
3. their wellbeing in the past two weeks.

There were no new questions in Questionnaire 2. Appendix I displays all the survey questions for Questionnaire 1 and Questionnaire 2. Later in this chapter section I detail how these questionnaire items developed during pre-test and pilot-test stages.

I now present, describe and justify the survey items covered by the alone-time questions, wellbeing scale, and demographic questions.

Alone-time questions

As there were no previously validated tools for measuring how and where alone-time might be spent, new questions needed to be developed for this survey. Items in Questionnaire 1 which asked about how and where alone-time was spent (1) were largely based on findings from the qualitative phase, (2) were multiple choice, and (3) included options for respondents to provide their own answers for options that weren't listed. For the questions about spaces and activities, several options were given for each in groupings that corresponded with how the qualitative respondents talked about those spaces and activities. For instance, creative activities were separated into "indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc." and "online or computer based creative activities including software design, coding, etc." but were also included in "outdoor recreation such as gardening, sitting in nature, slow walking, photography etc."

Wellbeing scale

At the time of the questionnaire development, no self-report wellbeing measures had been validated with autistic adults, although since then the PERMA profiler, a 23-item questionnaire measuring across five subscales of Positive emotion, Engagement, Relationships, Meaning and Accomplishment was shown to be potentially viable for autistic adults, with the exception of the Engagement subscale (Grosvenor *et al*., 2023). However, the 14-item Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) has been previously used with autistic adults in research studying, for instance, the effects on wellbeing of community connectedness and masking; autistic traits; and trait resilience and coping strategies (Cage *et al*., 2022; Stimpson *et al*., 2020; Muniandy *et al*., 2019).

The WEMWBS and the 7-item Short Warwick-Edinburgh Mental Well-Being Scale (SWEBWMS) were developed to support Public Health initiatives in monitoring and comparing positive mental health, and evaluating public health interventions, programmes and approaches to promoting mental health, particularly in non-clinical populations. Using qualitative methods, it was developed with members of the general public and with mental health service uses in Scotland and England. The scales were designed within a conceptual framework focussing entirely on positive aspects of mental health: the hedonic aspect of feeling good and the eudaimonic aspect of functioning well (Tennant *et al.,* 2007). This focus on positive subjective experiences contrasts with research into poor mental health which uses measures that seek to quantify an absence of happiness and psychological functioning. The developers of the WEMWBS and SWEMWBS aimed to build on previous scales and capture a wide conception of wellbeing, while being free of ceiling effects, which occur when individuals score minimum or maximum scores, meaning that improvements or deterioration in wellbeing cannot be measured. Both scales can be found in Appendix I

(Tables 3 & 4). For the purposes of this thesis the WEMWBS questions are itemised in Questionnaire 1 as Q9-22, and in Questionnaire 2 as Q3-16.

Benefits of the WEMWBS/SWEBWMS include that the scales are short, robust, accessible, and acceptable, and that they provide a single score (Stewart-Brown, 2014). The scales are freely available, with no financial cost involved in using them. However, the user must register to use the scales in research, and conditions, such as including the copyright statement and not changing the format of the scales, must be met. Both scales are considered to be robust and valid for use with different populations in the UK and globally; including ethnic minority groups in the UK, young adults with neurodevelopmental 'disorders' (of which autism was included), and the general population in Northern Ireland (Taggart *et al*., 2013; Appelqvist-Schmidlechner *et al*., 2020; Lloyd & Devine, 2012). However, either scale might be considered more or less appropriate in certain settings. The shorter, 7-point scale asks for less time from respondents, but may offer a more restricted view of wellbeing as it is weighted to more 'functioning' than 'feeling' items (Warwick Medical School, 2020).

Within exploratory sequential research-design, the quantitative feature (in this case, the survey questionnaire) should link to the themes, quotes and/or codes of the qualitative findings (Creswell & Plano Clark, 2018). The 14-point WEMWBS not only measures overall mental wellbeing, but has a number of points that closely relate to the final theme *ready to reconnect with others*, specifically (1) I've been feeling interested in other people, (2) I've had energy to spare, (3) I've been feeling close to other people, (4) I've been feeling confident and (5) I've been feeling loved. As the 7-point SWEMWBS does not include (1) I've had energy to spare, (2) I've been feeling confident and (3) I've been feeling loved, we (myself and the CAG) did not consider it as useful a choice of measure for the current study.

Demographic questions

From the outset of the research, I did not intend to adjust for confounders because, in the autistic population, identity characteristics such as gender are considered fluid and demographic characteristics such as employment status and financial situations tend to be complex and unstable over time. I considered that drawing conclusions based on demographic variables might not be valuable and could potentially cause suspicion in the autistic community, a stakeholder group which is already often mistrustful of autism research (Milton, 2014). Instead, I aimed to only include a minimum of demographic questions (Appendix I, Table 5) which, rather than being used as variables in the analysis, would only be used to see whether the needs and experiences of a diverse range of respondents were included. Further, we considered that minimising the time required to complete the questionnaire was important in reducing the burden to respondents. After discussion with the CAG it was decided that only gender, age, ethnic background, and highest educational qualification would be included. Other commonly included demographic questions such as sexuality and marital status were not felt to be relevant to the subject; and financial demographic questions such as those around employment and income were discussed but discarded as autistic people's employment status and financial situations are often fluid and complex, thus this question was likely to increase the burden of time investment for the respondents.

As the free version of Qualtrics limits the number of survey items, Q23-26 were presented in a matrix table. As such, 'not applicable' was included as a possible answer for all of them, rather than just the relevant questions. Q23 'do you live most or all of the year in the UK?' was included so that respondents selecting 'no' or 'not applicable' could be removed (numbers for excluded responses are provided later in this chapter). Invitations to take part in the survey requested 'autistic adults (aged 18 or over) who live in the UK'. Some questionnaire surveys only include participants with a clinical diagnosis of Autistic Spectrum Disorder or Asperger's Syndrome. However, studies which have compared answers between clinically diagnosed and self-identified autistic people have found little to no difference between the results (e.g. Charlton *et al*., 2021); additionally, the inclusion of demographic questions asking for a disclosure of a clinical diagnosis tend to cause mistrust in the autistic community. Some questionnaires include a screening process using commonly used diagnostic criteria but these are lengthy, and are increasingly not considered accurate measures. As such, anyone who identified as autistic, whether self-identified, professionally assessed or clinically diagnosed was eligible to be included in this survey (Q24).

Although invitations specified that the questionnaires be completed by autistic adults, I included Q25-26 (*"Are you filling in this questionnaire on behalf of someone else who is autistic"* and *"If you are completing this questionnaire on behalf of someone else, did you* *consult with them for each answer*?") for anyone who might have completed up to this point because they wanted to make sure someone's views were included who might not otherwise be able to access the Qualtrics platform and format. I had intended to include these questionnaires in the analysis, and compare results for interest. However, none of the questionnaires eligible for inclusion were completed on behalf of somebody else.

I carefully considered Q27, which asked for best descriptions of the respondent's gender and included the options 'not listed, please describe' and 'prefer not to answer', in order to be respectful of respondents' preferred gender descriptions. While some questionnaires offer cis- or het- options, I considered that these options were too intrusive and not necessary for this survey. Age brackets (Q28) were equally divided, with the exception of '18-30' and '81 or over'; and I included '17 or under' so that I could identify and exclude any responses not completed by adults.

Q29 categories were taken directly from England and Wales' List of Ethnic Groups (Gov.UK, 2021b) but without the sub-categories (e.g. Asian / Asian British is subcategorised as: Indian / Pakistani / Bangladeshi / Chinese / Any other Asian background) to reduce time and effort for respondents.

Ethics; data management and risk assessment

Ethical considerations for this quantitative study phase were similar to those of the earlier qualitative phase, as described in Chapter Three. In response to considerations made, as outlined for the qualitative phase and in this chapter so far, my ethical application was approved from UWE's Health and Applied Sciences Research Ethics Committee: UWE REC REF No: HAS.22.05.108 (Appendix J, and also see Appendix K for my data management plan).

Participant information sheet, research privacy notice and consent form

The participant information and consent items (Appendices L & M) were designed with clarity and accessibility in mind and were approved by the CAG. The research privacy notice (Appendix N), was identical to the research privacy notice created for the qualitative study, with the exception of the ethics approval number.

Design of survey delivery

In addition to usual online survey considerations around recruitment, distribution, collection and data protection, additional considerations were necessary to collect and collate Questionnaire 1 and Questionnaire 2 responses, while protecting respondents' privacy and right to anonymity. To (1) separate the respondents' data and email address, and (2) enable the collection and collation of repeat questionnaires, the flow of delivery was designed as follows:

1. Through social media, respondents were invited to take part via an online link to Questionnaire 1.
2. Questionnaire 1 included (1) participant information (including a hyperlink to the research privacy notice), (2) the consent form, (3) instructions for creating a unique user identifier (UUI), (4) the survey questions, and (5) a hyperlink to Questionnaire 1a (where respondents could provide their email address).
3. Two weeks after Questionnaire 1a was submitted, an anonymous link to Questionnaire 2 was emailed to each respondent. Questionnaire 2 included instructions for recalling the respondent's UUI. A reminder to complete Questionnaire 2 was emailed four days later.

In this way, email addresses were kept separately from the questionnaires and the questionnaires could be collated using the UUI.

Designing for accessibility

In creating the survey, I followed guidance on designing accessible surveys by Aidley and Fearon (2021), including keeping the survey length as short as possible and making questions as clear as possible. The integrated survey accessibility checker in Qualtrics flagged only minor but unavoidable points. For instance, matrix style questions are not ideal for accessibility, but the WEBWMS registration states that the scale can only be presented in its original format. However, the phone version of the survey automatically presented matrix questions as individual multiple-choice questions.

Questionnaire pre-test

Questionnaire design should consider validity concerns, the relevance and clarity of the questionnaire questions, and the accuracy with which the questions can measure what they are designed to measure (Pilkington, 2020b; Bray, 2020a). A questionnaire cannot be reliable if there are inconsistencies between how items are understood by participants, or if the results can be interpreted differently by different researchers (Boynton & Greenhalgh, 2004). Unfortunately, survey instruments commonly used in the general population are often inaccessible and frustrating for autistic adults, raising concerns about the validity of such tools for use with autistic participants, and even the potential to do harm (Stacey & Cage, 2022; Nicolaidis *et al*., 2019).

Pre-testing of the questionnaire items (presented in a Word document) was carried out by the CAG and a few selected friends and colleagues (ten in total, of whom most but not all are autistic) to check (1) clarity of explanations and questions, and (2) accessibility of explanations and questions. As a result of pre-testing, minor changes were made to my original wording in several places.

Questionnaire pilot

Pilot studies can be useful in ensuring that self-administered questionnaires 'do what they are designed to do' in terms of improving study logistics, reducing ambiguity in questionnaire items, generating additional fixed-choice answers and pinpointing language, technical or ethical problems that may be present (Bryman, 2016; Ruel *et al*., 2016). I carried out a pilot test with 26 participants, some of whom were autistic friends, and some of whom were recruited via Twitter and were unknown to me, to evaluate the following:

1. Study logistics for the respondents.
2. Study logistics for myself as researcher, such as whether the data could be exported.
3. Content validity: whether the data measured what it was designed to measure.
4. Face validity: assessing whether questions were unambiguous and measured what they were designed to measure.
5. Questionnaire flow of delivery: that the questionnaires were received in a correct and timely manner.

6. Visual design: that the questionnaire was easy to read and complete on a variety of screen interfaces.
7. Readability: that all areas of the process were easy to read and understand, including the invitation to take part, consent form and emails.

At the end of each questionnaire I asked the test participants for general feedback on the recruitment process, flow of questionnaire design, whether the questionnaires were easy to understand and complete, how long the questionnaires took to complete, and whether they had any concerns about the study.

Several changes were made to both questionnaires as a result of feedback (original version in Appendix O) and so, when I emailed the test participants to thank them for their input I also outlined the key changes to the test participants to acknowledge their input into the design of the final survey.

Study logistics for the participants

The test participants reported that Questionnaire 1 took under or around ten minutes to complete, and that Questionnaire 2 took under five minutes. I included these timings in the final survey invitations and information.

Questionnaire 1 originally listed alone-time activities and spaces twice, firstly as a "*tick all that apply*" and secondly asking participants to put the three activities/spaces that they felt were most important into numerical order. Although the numbering system had been chosen to replace a standard, but not fully accessible drag-and-drop option in Qualtrics, several test participants reported finding the numbering cognitively and practically inaccessible and so the second option was changed as a "*tick just one*" for the activity/space that was felt to be most important.

Study logistics for the researcher

Data from the pilot test was successfully exported from Qualtrics to Microsoft Excel; and from Microsoft Excel to SPSS (Statistical Package for Social Sciences 28) and so no changes needed to be made.

Content validity

The questions about how and where participants chose to spend their alone time were originally phrased in terms of the past two weeks, e.g. "*What did you do during any alone-time over the past two weeks? (tick all that apply)*." Several test participants expressed concerns with this, namely (1) that not having had any alone time in the past two weeks caused them to feel excluded and frustrated that they couldn't fill in this section, and (2) that the previous two weeks had not been representative of how and where they usually spent their alone-time. As a result, I changed these questions to a more general, e.g. "*What do you like to do during your alone-time*" to avoid distressing people in this way and increase the chances of more generalisable survey results. Further, as this meant that repeating Q1, 4, 5, 6, 7 and 8 in Questionnaire 2 would now be redundant, the two-part survey would now ask for less time overall from the respondents, and create less unnecessary data for analysis. Finally, with the descriptive questions confined to Questionnaire 1, the descriptive analysis would no longer be reliant on both questionnaires being returned; subsequently, only RQ3, "*Is there an association between using this time and space, and self-reported wellbeing levels?*" would now require the data from both Questionnaire 1 and Questionnaire 2.

I had originally planned to deliver the two questionnaires four weeks apart, but to save time during the pilot test I delivered the questionnaires two weeks apart. Following the pilot test, I reviewed the questions that I wanted to quantitatively analyse. I had planned to look for associations between alone-time had, alone-time wanted and wellbeing; and to see if these associations held for respondents at different time points, four weeks apart. As I reviewed my sub-questions it became apparent that by spacing the final questionnaires two weeks apart, rather than four weeks, it would be possible to look for associations between the exposure variables (i.e. alone-time had, alone-time wanted and the difference between these two variables) and the outcome variable (the wellbeing score) between time point 1 and time point 2 (discussed further later in this chapter). As such, the two-week spacing for convenience during the pilot test phase remained a two-week spacing in the final survey for more refined analytic questions.

Face validity

While testing Questionnaire 1, some of the test participants noted that they needed more context and clarity from the provided definition of alone time, particularly “you are in a space where you won’t be interrupted or distracted by other people.” Two said that having children at home during holidays or home educating meant that alone-time was technically impossible, one said that having family at home was preferable, but that interacting was overwhelming; another said that having other people in the house left her in a constant state of vigilance. To ensure clearer, more inclusive and more relevant data for analysis, I added an additional multiple-choice question to the pilot version of Questionnaire 2, to be later included only in the final version of Questionnaire 1, ‘*Could you please tell me what "you are in a space where you won't be interrupted or distracted by other people" means for you?’* General feedback showed that the test participants appreciated being able to clarify their own interpretation of this aspect of ‘alone-time’.

To address concerns from participants at the pilot-test stage the final questionnaire versions included assurances that (1) alone-time could be spent with animals, (2) working could still count as alone-time, as long as the above criteria was still met, and (3) normal sleep hours did not count as alone-time.

Other than the consent questions, all fields could be skipped. However, none of the test participants skipped any questions.

Several of the test participants ‘not listed, please describe’ answers were also incorporated into the multiple-choice questions. In particular, the final categories in Q3-7 were developed and finalised using (1) data from the qualitative interviews, (2) previous community knowledge, (3) feedback from the CAG, and (4) feedback from the test participants.

Visual design

With the free version of Qualtrics, very little can be done to change the visual design. However, following technical feedback from one participant that tackling questionnaires from a user-point of view is easier when the sections are split into pages, I used page breaks to separate out different parts of each questionnaire.

Questionnaire flow of delivery

Twenty-six people responded to my Instagram and Twitter requests for test participants over the course of a weekend and promptly completed Questionnaire 1 and Questionnaire 1a. Two test participants reported that they had missed the link to Questionnaire 1a and so I sent it to them directly. Nineteen test participants completed Questionnaire 2 within a week of receiving the link via email, and a further two completed Questionnaire 2 within a week of a reminder email. I did not send a second reminder email and I did not consider that any further changes needed to be made to the flow of delivery for the finalised survey.

As such, when the final questionnaire was launched, my daily task-list was to:

1. Copy all new email addresses submitted to Questionnaire 1a in the past 24 hours into a new OneDrive file labelled with that day's date.
2. Email an invitation to take part in Questionnaire 2 to everyone listed on the file labelled with the two weeks previous date (sent blind carbon copy).
3. Email a reminder to take part in Questionnaire 2 to everyone listed on the file labelled with the two weeks and four days previous date (sent blind carbon copy) and then delete that file.

The invitation and reminder can be found in Appendix P.

Readability

Only minor issues were picked up around the clarity of some of the questions, and these were easily resolved.

5.2 Quantitative data collection and analytic methods

In this chapter's second section I explain the rationale and process for the sampling and recruitment processes I used, and then detail the data collection itself before presenting the statistical analysis methods.

Sampling

Probability sampling, randomly selecting a sample from a sampling frame (a list of people from the population being researched) is generally recommended for survey research as everyone from the target population has an equal chance of being included in the study.

However, a list of people from whom to sample is not possible in research with autistic adults: there are no definitive lists of autistic adults in the UK. Additionally, it is not possible for any autism study to claim representativeness: as discussed in Chapter One, autism is not equally recognised or diagnosed across demographics such as age, gender, ethnicity, geographical location and socio-economic status (Roman-Urrestarazu *et al*., 2022). Convenience sampling (a pragmatic approach in which participants are targeted for ease of reach) combined with snowball sampling (through which participants or interested parties share or recruit further participants) were therefore appropriate for this survey. I was unable to tell whether or not participants from the qualitative phase had also completed the survey, and so the samples are likely to have been predominantly parallel (different individuals but from the same population) but may have also been partly nested (i.e. meaning that some of the qualitative participants may have been a subset of the survey respondents).

Sample size

Sample sizes for questionnaire surveys conducted with autistic adults tend to be lower than those conducted with the general population. Following a search of all quantitative and/or mixed-methods surveys conducted with autistic adults in the UK which were published in 2021, I noted that sample sizes ranged from 109 to 288 participants, had a median sample size of 212, and that all but one had under 250 participants. These figures were used to guide anticipated recruitment numbers for the current survey. Thus, I hoped to recruit at least 250 respondents for Questionnaire 1, and, allowing for a 50% drop-out rate, assumed that at least 125 would return to complete Questionnaire 2.

Recruitment

Social media sites such as Twitter have been used for some time to recruit for questionnaire surveys. O’Connor’s *et al*. (2013) discussion of recruiting via Twitter in 2012 for a health research survey found that Twitter enabled speedy engagement with populations that are typically less represented, and was also beneficial in terms of transparency, anonymity and accessibility. Using snowball technique sampling, they were able to recruit a heterogenous sample. However, they noted that, as with any other online sampling it was not possible to verify personal information.

Between the 13th October 2022 and the 15th December 2022, I tweeted links to the survey at least once, on most days. I also shared those tweets directly with selected personal accounts of autistic adults in the UK - a pragmatic method of reaching additional members of the target population, i.e. autistic adults based in the UK. These tweets were shared by followers, and in turn by their followers, a snowballing effect which widened the reach considerably and made it more likely that a range of different autistic demographic populations in the UK would be reached. Additionally, I asked in tweets for people to share the questionnaire link via other social media, such as Facebook, for an increased reach.

I made use of a few techniques to improve reach amongst online autistic communities: (1) on Twitter I wrote a thread of tweets describing the purpose of the study and what respondents should expect in terms of questions and time outlay; and wrote a similarly long caption for my initial Instagram post, and (2) over the following few weeks I tried a variety of tweet and retweet styles at different times of day, sometimes using commonly used and targeted hashtags including, but not limited to, #ActuallyAutistic, #AskingAutistics and #AutisticsInAcademia. While engagement was steady for the first four weeks of recruitment there was a noticeable drop in tweet engagement following Elon Musk's takeover of, and subsequent changes to Twitter, during which paid accounts were given visibility priority over non-paid accounts. Outside of social media, details of the survey were also shared with UWE's student union, university-based neurodiversity groups at UWE and the University of Bristol, and autism support groups; however, there were no noticeable increases in recruitment following these shares.

Data collection

I began data collection on 13th October 2022 and closed Questionnaire 1 on the 17th December 2022 with 407 responses. Of these, four responses were immediately deleted as these respondents had selected "no" for one or more consent options. As one of the consent criteria was that responses would only be included for analysis if the respondent had clicked the 'submit' button at the end of the questionnaire, a further 120 responses were also deleted. Of those non-submitted responses, most respondents had ceased filling in the questionnaire at only 11% and 33% completion, meaning that very little usable data would have been collected even if they had been included. 17 responses were excluded from respondents not living in the UK (11 selected 'no', six did not select either 'yes' or 'no'), and a further three were excluded from respondents who were not autistic (one selected ‘n/a’, one selected ’no’, and one did not select any option. None of the remaining respondents completed the questionnaire on behalf of someone else. A further 19 responses which were used in the descriptive analysis were not used in the correlation analysis due to missing data, data outliers and unusable text responses. Exclusion rates are shown in Tables 5.2 and 5.3, and exclusion reasons are discussed further in Chapter Six.

Table 5.2: Reasons for excluded Questionnaire 1 responses

Questionnaire 1	Excluded responses	Running total
Responses recorded on Qualtrics	-	407
Full consent not given	4	403
Incomplete responses	116	287
Respondents not UK based	17	270
Respondents not autistic	3	**Total for descriptive analysis: 267**
Missing data (alone-time hours had or wanted)	3	264
Outliers (18+ alone-time hours had or wanted)	14	250
Unusable text responses for numerical data	3	**Total for correlation analysis: 247**

249 respondents left their email addresses using Questionnaire 1a and one respondent emailed separately to request that their email address be included as they had accidentally clicked past the hyperlink for Questionnaire 1a. Final reminders for Questionnaire 2 were

sent on the 2nd January 2023, allowing time for any last responses. I then closed Questionnaire 2 on the 5th January with 211 responses. Of these, all respondents gave full consent. Nine responses were discarded as they were incomplete. The unique user identifier (UUI) was used to match respondents' answers for Questionnaire 1 and Questionnaire 2; 32 responses were discarded as the UUIs did not match up with Questionnaire 1 UUIs.

Table 5.3: Reasons for excluded Questionnaire 2 responses

Questionnaire 2	Excluded responses	Running total
Responses recorded on Qualtrics	-	211
Full consent not given	0	211
Incomplete responses	9	**Total responses for descriptive analysis: 202**
Missing data (hours had or wanted) or long text responses	16	186
Outliers (18+ hours had or wanted)	8	178
Questionnaire 2 responses did not match with Questionnaire 1 UUIs	32	**Total responses for correlation analysis: 146**

The way the two questionnaires were designed to collect data meant that there were a variety of response numbers available for answering different quantitative questions, from 267 responses valid for describing how and where people preferred to spend alone time, to 146 valid for assessing associations between the amount of alone-time wanted and had, and wellbeing scores. In Chapter Six, in which I present and discuss the analysis, I state the number of responses for each analysis.

Statistical analysis methods

I answered RQ2: "How and where do they choose to spend this time?" with descriptive analysis, which highlights patterns in data. I manually copied the data from 267

Questionnaire 1 responses and 202 Questionnaire 2 responses directly from Qualtrics, which displays counts and percentages of options, to create tables and bar charts in Microsoft Excel (presented and discussed in the following chapter) showing:

1. Clarifications of what 'alone-time' meant to respondents
2. Most popular alone-time activities
3. Alone-time activities felt to be most important for wellbeing
4. Most popular spaces to spend alone-time in
5. Indoor spaces felt to be most important for wellbeing
6. Outdoor spaces felt to be most important for wellbeing

I then answered RQ3: "Is there an association between using this time and space, and self-reported levels of wellbeing?" with correlation analysis, which is used to estimate relationships between a dependent variable and one or more independent variables. Once I had uploaded and cleaned the Qualtrics data into Microsoft Excel, and removed all responses not eligible for analysis (see above, Data Collection), I uploaded the Excel data into SPSS. Due to attrition (the drop-out rate between time points), there were 101 fewer eligible responses to Questionnaire 2 than for Questionnaire 1. Where possible I included the larger Questionnaire 1 sample in statistical tests as the sample was already quite small, but carried out sensitivity testing where necessary to check for consistency. As such, I analysed 247 Questionnaire 1 responses and 146 Questionnaire 2 responses to answer the following five sub-questions.

RQ3.1: Is there a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point?

The hypotheses I am testing are:

> H_0: There is no difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point
>
> H_1: There is a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point

The exposure variable (the independent variable which may explain or predict a study outcome) is, for the purpose of RQ3, the difference between alone-time *had*, and alone-time *wanted*. I created histograms (used to show the distribution of a single continuous variable) to show the distribution on the exposure variable at each time point.

The histograms showed reasonably Normal distributions but it was unclear whether the amount of alone-time had, was significantly different from the amount of alone-time wanted, at each time point. Therefore, it was appropriate to run one-sample t-tests, to check whether there was any evidence of a difference. I ran these in SPSS using the exposure variable for each time point.

RQ3.2: Is there a relationship between the difference between alone-time wanted and alone-time had at time point 1 with the change in wellbeing from time point 1 to time point 2?

> H_0: There is no relationship between the difference between alone-time wanted and alone-time had at time point 1, and the change in wellbeing from time point 1 to time point 2
>
> H_1: There is a relationship between the difference between alone-time wanted and alone-time had at time point 1, and the change in wellbeing from time point 1 to time point 2

This analysis assessed whether respondents who did not get the amount of alone-time that they wanted would see a decrease in wellbeing between time point 1 and time point 2.

The outcome variable (the dependent variable which may be affected by the exposure variable) is, for the purpose of RQ3, the wellbeing score for the previous two weeks as reported by the respondents. In SPSS I created histograms to show the distribution of the outcome variable.

To investigate the relationship between the exposure variable and the difference between the outcome variables at time point 1 and time point 2 I created a scatterplot (used to explore the difference between two continuous variables).

Correlation analyses are used to explore the direction of (i.e. positive or negative) and the strength of the relationships between two continuous variables. I ran a correlation analysis to investigate the relationship between the exposure variable at time point 1 with the difference in outcome variables between time point 1 and time point 2.

RQ3.3: Is there a relationship between this difference and wellbeing at the same time point?

> H_0: There is no relationship between the difference between alone-time wanted and alone-time had at each time point, and wellbeing at the same time point
>
> H_1: There is a relationship between the difference between alone-time wanted and alone-time had at each time point, and wellbeing at the same time point

This analysis assessed whether respondents who did not get the amount of alone-time that they wanted would experience lower wellbeing at that same time point.

To investigate the relationship between the exposure and the outcome variables at each time point I created two scatterplots. Each compared the exposure variable of the difference between alone-time wanted and alone-time had, with the outcome variable of the WEMWBS wellbeing total score.

As the exposure variable and outcome variables both showed Normal distributions, it was then appropriate to run Pearson's *r* correlation analyses to assess whether there was evidence of a correlation.

RQ3.4: Is there an association between the number of alone-time hours had at each time point, and wellbeing at the same time point?

> H_0: There is no association between the number of alone-time hours had at each time point, and wellbeing at the same time point
>
> H_1: There is an association between the number of alone-time hours had at each time point, and wellbeing at the same time point

This analysis assessed whether respondents who had high amounts of alone-time experienced higher wellbeing.

A cross-sectional (i.e. at the same time point) analysis looked assessed whether the amount of alone-time had showed a relationship with wellbeing. For this I created scatterplots and ran Pearson's *r* correlation analyses.

RQ3.5: Is there an association with wellbeing at time point 1 and the number of alone-time hours wanted at time point 2?

> H_0: There is no association between wellbeing at time point 1 AND the number of alone-time hours wanted at time point 2
>
> H_1: There is an association between wellbeing at time point 1 AND the number of alone-time hours wanted at time point 2

This final analysis assessed whether respondents who had low wellbeing at time point 1 might need or want higher amounts of alone-time at time point 2.

A cross-sectional analysis assessed whether wellbeing at time-point 1 had a relationship with the amount of alone-time wanted at time point 2. For this I created a scatterplot and ran a Pearson's *r* correlation analysis.

Chapter conclusion

This chapter described the development, data collection and statistical analysis methods for the quantitative phase. In line with sequential mixed methods research design, most of the survey items were generated from the earlier qualitative exploration, specifically, the categories of where and when alone-time was preferred and felt to be beneficial for wellbeing, and the inclusion of the WEMWBS. Embedding autistic experiences into the survey development increased the cultural and contextual sensitivity of the survey, an aspect that will be discussed further in Chapter Six, following the presentation and discussion of the quantitative results.

Chapter Six: Quantitative Results and Discussion, and Interpretation of the Integration

> "Reflecting on my time in solitary confinement and its impact on suicidality… let's not put people in low arousal, sensory and socially deprived spaces and expect to them to thrive because autistic people 'like to be alone'."
>
> - *Alexis Quinn (2023), autistic author (via twitter).*

This chapter firstly presents and discusses the results of the quantitative phase, for which I collected and analysed data from two online questionnaires and, secondly, draws conclusions about the integration of the mixed-methods phases. Through Questionnaire 1 I aimed to gain generalisable insights into how and where autistic adults choose to spend alone-time, and to ascertain which activities and spaces autistic adults feel are most beneficial for their wellbeing. Questionnaire 2, in conjunction with Questionnaire 1, was designed to look for associations between the amount of alone-time had, the amount of alone-time wanted, and wellbeing according to the Warwick Edinburgh Measure of Well-Being Scale (WEMWBS). As the previous chapter described the quantitative methodology, this chapter (1) reports the respondents' demographic characteristics, (2) presents the results for RQ2 and RQ3, and (3) discusses these results in relation to existing literature. Finally, (4) I reflect on the integration of the qualitative and quantitative phases.

6.1 Respondents' demographic characteristics

267 questionnaire responses were eligible for inclusion in the first descriptive analyses (see previous chapter for breakdown of exclusions). Table 6.1 displays the counts and percentages for the provided demographic characteristics of those respondents, and the free text entries for characteristics which had not been provided in the questionnaire. To reduce the burden on respondents' time, I did not ask for demographic information in the second questionnaire. As most of the eligible Questionnaire 1 respondents were also included in the combined analyses it is likely that Questionnaire 2 would be similarly represented.

Table 6.1: Demographic characteristics of Questionnaire 1 respondents (*n*=267)

	N (%)	Free text
"Which of the following best describes your gender?"		
Female	164 (61.42)	
Male	56 (20.97)	
Non-binary	40 (14.98)	
Not listed, please describe	6 (2.25)	Genderfluid, Male presenting, Undecided, Autigender, Intersex spectrum, Genderqueer
"How old are you?"		
18-30	66 (24.72)	
31-40	74 (27.72)	
41-50	72 (26.97)	
51-60	49 (18.35)	
61-70	5 (1.87)	
71-80	1 (0.37)	
"What is your ethnic background?"		
White	250 (93.63)	
Mixed/multiple ethnic	4 (1.5)	
Asian/Asian British	2 (0.75)	
Back/African/Caribbean/Black British	6 (6.25)	
Not listed, please describe	5 (1.87)	White European, Jewish, Mediterranean, British Cypriot, White other
"Please select the highest level of education you have attained"		
GCSE / O level or equivalent	16 (6.02%)	
A level or equivalent	31 (11.65)	
Trade, technical or vocational training	11 (4.14)	
Bachelor's degree or equivalent	70 (26.32)	
Postgraduate qualification	127 (47.74)	
Not listed, please describe	11 (4.14)	AS level, Foundation degree, Dutch MBO, PhD, Scottish NC, Certificate of Higher Education, Higher National Certificate, Masters, MSc

164 respondents (61.4%) of the sample identified as female, with only 56 (21%) identifying as male and 40 (15%) as non-binary. Six respondents (2.3%) who did not feel represented by the listed options provided their own gender identities (listed in Table 6.1 under 'free text'). Age brackets were represented fairly evenly between 18 and 60 (24.7%, 27.8%, 27.0%, 18.4%), with just 6 (2.2%) of respondents aged over 61. There was a notable lack of ethnic diversity in the sample (recorded in line with British census main categories), with 250 respondents (93.6%) selecting 'white', and other respondents including 'white' as an unlisted option. 197 (74.1%) of respondents had at least a Bachelor's degree (or equivalent), with the majority of these also having a post-graduate qualification. While the generalisability of the findings is impacted by a narrow demographic spread, the unique insights gained are nonetheless valuable in understanding potential wellbeing benefits of alone-time for the UK autistic population.

6.2 Results

In this section, I first build on qualitative findings by quantitatively answering RQ2: "How and where do they choose to spend this time?" I then aim to fully answer RQ3: "Is there an association between using this time and space, and self-reported levels of wellbeing?"

RQ2: How and where do autistic adults choose to spend their alone time?

Please note that, in this thesis chapter, italics within quotation marks indicate questionnaire items verbatim.

What alone-time means to respondents.

The first survey question, delivered in the first questionnaire only, aimed to clarify what 'alone-time' meant to the respondents. This question was added to the survey after feedback from several of the test participants, which showed that some were not sure how to interpret one of the three provided descriptions of alone-time as defined in the questionnaire, "you are in a space where you aren't interrupted or distracted by other people".

"Q1: For the first section of this questionnaire I will be asking you about alone-time. Some people refer to alone-time as me-time or decompression-time. My research so far has shown that alone-time probably needs each of these to be true:

(1) you are in a space where you aren't interrupted or distracted by other people

(2) you are in a space where you feel comfortable

(3) you are able to choose what you do

(Please note that, in this study, alone-time can be spent with animals, and it can be when you are working. It can include napping, but should not include your usual sleep time).

Some people find that they need to be completely alone for alone-time and others can still enjoy alone-time when other people are near them. What do you need?"

Table 6.2: Respondents' requirements for not feeling interrupted or distracted by other people (*n*=266)

Requirements for alone-time	***N***	**%**
I need to be completely alone with no chance of anyone interrupting or distracting me	100	37.59%
I need to be alone where it is unlikely that anyone will interrupt or distract me.	111	41.73%
I don't need to be alone but I need people not to interact with me.	41	15.41%
None of the above, please describe:	14	5.26%

A free text box was included for the category 'none of the above, please describe'. All 14 text responses were contextual and included "*I need to be alone but feel more comfortable if other people are in the house or I know that people are close by*", "*I feel it is a mixture of all three for me. It definitely fluctuates over time and depending on my current needs at the time*", and "*I need to be completely alone for with no chance of anyone interrupting or distracting me, but that's really hard to get. So, I will often accept whatever I can get*."

The category "I need to be alone where it is unlikely that anyone will interrupt or distract me" was the highest selected option with 41.7% of respondents, but was closely followed by "I need to be completely alone with no chance of anyone interrupting or distracting me" at 37.6%. This indicates that most respondents do actually need to be physically alone for their time to be considered alone-time. However, 15.4% of respondents selecting "I don't need to be alone but I need people not to interact with me” suggests that solitary activities adequately engage this subgroup enough that they do not experience unwelcome social and/or sensory distraction from others.

How respondents choose to spend their alone-time

The following two survey questions, delivered only in Questionnaire 1, aimed to (1) list the most popular alone-time activities, and (2) find out which alone-time activities the respondents felt were most important for their wellbeing.

“Q4: What do you like to do during your alone-time? (Tick all that apply). Please remember that, in this study, alone-time might include paid work as long as (1) you are in a space where you won't be interrupted or distracted by other people, (2) you are in a space where you feel comfortable and (3) you are able to choose what you do.”

The categories listed in Table 6.3 were developed from (1) data from the qualitative interviews, (2) previous community knowledge, (3) feedback from the community advisory group (CAG), and (4) feedback from test participants. Please note that bar charts visually representing all descriptive analyses can be found in Appendix Q.

Table 6.3: Activities enjoyed during alone-time (*n*=265). Note the percentages do not add up to 100 as respondents were able to select multiple answers.

Activity category	*N*	%
Read, watch TV or films, listen to audio books, podcasts, music or the radio etc.	236	89.06%
Indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc.	144	54.34%
Gaming	100	37.74%
Creative activities such as software design and coding	22	8.30%
Hands-on projects such as DIY, bike maintenance, woodwork etc.	40	15.09%
Study an area of interest (books, papers, online etc.)	157	59.25%
Jigsaws, crosswords, Sudoku, Wordle etc.	70	26.42%
Social media	163	61.51%
Mindfulness, yoga, meditation etc.	59	22.26%
Stimming	97	36.60%
Napping or being still	140	52.83%
Exercising (such as cardio, strength, or flexibility training)	63	23.77%
Gentle outdoor recreation such as sitting in nature, slow walking etc.	93	35.09%
Outdoor physical activity such as long-distance hiking, wild swimming, biking etc.	38	14.34%
Commuting or travel time alone (such as walking, cycling, driving, public transport)	57	21.51%
Outdoor creative activities such as gardening, drawing, photography etc.	47	17.74%

An open text box for respondents to add activities not listed was provided. Of the 42 text responses, almost all were covered by the categories provided. Exceptions included shopping, cuddling animals, masturbating, housework, eating and bathing.

By far, the most popular alone-time activity category covered reading, watching or listening, with 236 of 265 respondents engaging with books, TV, podcasts and the radio etc. during their alone-time. In order of preference, social media, studying an area of interest, indoor creative activities and napping or being still were the next most popular activities with between 140 and 163 of respondents selecting these options.

"Q5: Which one of the following feels the most important for your wellbeing? (Tick just one)."

The categories in Table 6.4 are identical to those listed for the most popular activities (Table 6.3).

Table 6.4: Most important alone-time activities for wellbeing (*n*=265).

Activity category	***N***	**%**
Read, watch TV or films, listen to audio books, podcasts, music or the radio etc.	58	21.89%
Indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc.	40	15.09%
Gaming	16	6.04%
Creative activities such as software design and coding	2	0.75%
Hands-on projects such as DIY, bike maintenance, woodwork etc.	1	0.38%
Study an area of interest (books, papers, online etc.)	11	4.15%
Jigsaws, crosswords, Sudoku, Wordle etc.	1	0.38%
Social media	6	2.26%
Mindfulness, yoga, meditation etc.	8	3.02%
Stimming	9	3.40%
Napping or being still	44	16.6%
Exercising (such as cardio, strength, or flexibility training)	8	3.02%
Gentle outdoor recreation such as sitting in nature, slow walked etc.	29	10.94%
Outdoor physical activity such as long-distance hiking, wild swimming, biking etc.	10	3.77%
Commuting or travel time alone (such as walking, cycling, driving, public transport)	3	1.13%
Outdoor creative activities such as gardening, drawing, photography etc.	2	0.75%
Not listed, please describe	17	6.42%

An open text box for respondents to add activities felt to be most important for their wellbeing was provided. Of the 17 responses to “not listed, please describe” almost all were covered in the categories listed above with the exception of bathing/hydrotherapy.

With the exception of studying an area of interest, the top five most-popular alone-time activities are also represented in the top five most important alone-time wellbeing activities. 21.9% of respondents felt that reading, watching or listening was the most important for their wellbeing, 16.6% preferred napping or being still, 15.1% chose indoor creative activities, and 10.9% felt that spending their time outside, taking part in gentle recreation activities, was the most important for wellbeing. All other categories were represented by at least 0.4% but no more than 6.1% of respondents' preferences.

Where respondents choose to spend their alone-time

The following three survey questions, delivered only in Questionnaire 1, aimed to (1) list the most popular alone-time spaces, and (2) find out which alone-time spaces the respondents felt were most important for their wellbeing.

"Q6: Where do you like to spend your alone-time? (Tick all that apply even if there are overlaps)."

The following categories (Table 6.5) were developed from (1) data from the qualitative interviews, (2) previous community knowledge, (3) feedback from the community advisory group (CAG), and (4) feedback from pilot-test participants.

Table 6.5: Most popular spaces to spend alone-time (*n*=265). Note the percentages do not add up to 100 as respondents were able to select multiple answers.

Environment category	***N***	**%**
Indoor spaces where you have control over heating, lighting, visuals, noise etc.	241	90.94%
Indoor spaces where you do not have much control over heating, lighting, visuals, noise etc.	9	3.34%
Indoor spaces with hardly any sensory distractions (audio, visual etc.)	115	43.40%
Indoor spaces that are interesting for your senses (visuals, music, scents etc.)	73	27.55%
Indoor spaces that feel cosy	178	67.17%
Indoor spaces that feel safe	202	76.23%
Indoor spaces that have everything you need for your favourite activities	166	62.64%
Outdoor spaces where there are several or lots of people nearby	4	1.51%
Outdoor spaces where there are no or very few people nearby	124	46.79%
Maintained natural or rural outdoor spaces (such as local parks or public/private gardens)	80	30.19%
Natural or rural outdoor spaces (such as National Parks, woodlands or beaches)	119	44.91%
Urban spaces (such as city streets or busy shopping areas)	17	6.42%
Familiar outdoor spaces (places you know well)	98	36.98%
Unfamiliar outdoor spaces (places you don't know well)	22	8.30%
An outdoor space with hardly any sensory distractions (audio, visual, olfactory etc.)	29	10.94%
An outdoor space that is interesting for your senses (audio, visual, olfactory etc.)	68	25.66%
Not listed, please describe	7	2.64%

An open text box for respondents to add activities not listed was provided. All seven text responses were either covered by the provided categories or were activities rather than environmental descriptions.

The first four most popular environmental spaces are all indoor and describe spaces that can be adapted by/for the individual, including sensory control (241 respondents), feeling safe (202) and feeling cosy (178), and being set up for favourite activities (166). These are followed by two outdoor criteria: spaces with very few other people (124), and spaces which are natural or rural (119).

"Q7: Which one of the following indoor spaces feels the most important for your wellbeing? (Tick just one)."

The categories in Table 6.6 are identical to those listed for the most popular indoor spaces (Table 6.5).

Table 6.6: Indoor spaces felt most important for wellbeing (*n*=265).

Indoor environment category	***N***	**%**
An indoor space where you have control over heating, lighting, visuals, noise etc.	149	56.02%
An indoor space where you do not have much control over heating, lighting, visuals, noise etc.	0	0.00%
An indoor space with hardly any sensory distractions (audio, visual etc.)	14	5.26%
An indoor space that is interesting for your senses (visual, music, scents etc.)	2	0.75%
An indoor space that feels cosy	21	7.89%
An indoor space that feels safe	56	21.05%
An indoor space that has everything you need for your favourite activities	22	8.27%
Not listed, please describe	2	0.75%

An open text box for respondents to add indoor spaces not listed was provided. Of the two text responses, one wrote ‘home’ and the other described an activity.

56.0% of respondents felt that having control over the sensory aspects of an indoor space was the most important for their wellbeing (in contrast, no respondents felt that not having control over the sensory aspects was the most important for their wellbeing) and 21.1% of respondents felt that the most important criteria for wellbeing was that an indoor space should feel safe. All other criteria were selected by 8.3% of respondents or fewer.

“Q8: Which one of the following outdoor spaces feels the most important for your wellbeing? (Tick just one).”

The categories in Table 6.7 are identical to those listed for the most popular outdoor spaces (Table 6.5).

Table 6.7: Outdoor spaces felt most important for wellbeing (*n*=265).

Outdoor environment category	***N***	**%**
An outdoor space where there are several or lots of other people nearby	1	0.38%
An outdoor space where there are no or very few people nearby	76	28.68%
A maintained natural or rural outdoor space (such as a local park or a public/private garden)	18	6.79%
A natural or rural outdoor space (such as a National Park, woodland or a beach)	87	32.83%
An urban space (such as city streets or a busy shopping area)	3	1.13%
A familiar outdoor space (somewhere you know well)	40	15.09%
An unfamiliar outdoor space (somewhere you don't know well)	0	0.00%
An outdoor space with hardly any sensory distractions (audio, visual, olfactory etc.)	12	4.53%
an outdoor space that is interesting for your senses (audio, visual, olfactory etc.)	21	7.92%
Not listed, please describe	7	2.64%

An open text box for respondents to add outdoor spaces not listed was provided. Of the seven text responses, almost all were covered by the categories listed above or named a specific outdoor environment like woodland or the seafront. One text response stated "I don't feel comfortable or able to relax outdoors. I mean I like the outdoors but it's not my calm place."

As with the most popular outdoor spaces, natural or rural outdoor spaces, and spaces where there were few people nearby were considered the most important for wellbeing (32.8% and 29.0% respectively). Familiarity was felt to be the next most important (15.1%) and all other options were selected by 8.0% of respondents or fewer.

RQ3: Is there an association between using this time and space, and self-reported levels of wellbeing?

Three questionnaire items were included to assess associations between alone-time and wellbeing: (1) how many daily average hours of alone-time respondents had experienced (henceforth referred to as alone-time *had*) in the past two weeks, (2) how many daily average hours of alone-time respondents had needed or wanted in the past two weeks (henceforth only referred to as alone-time *wanted*), and (3) the respondents' Warwick Edinburgh Mental Well-Being Scale (WEMWBS) total scores in the past two weeks (henceforth referred to as *wellbeing*). As described in Chapter Five, I used correlation analyses to answer the following five questions:

RQ3.1: Is there a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point?

RQ3.2: Is there a relationship between this difference and wellbeing at the same time point?

RQ3.3: Is there a relationship between the difference between alone-time wanted and alone-time had at time point 1 with the change in wellbeing at both time points?

RQ3.4: Is there an association between the number of alone-time hours had at each time point, and wellbeing at the same time point?

RQ3.5: Is there an association with wellbeing at time point 1 and the number of alone-time hours wanted at time point 2?

Please note that 'time point 1' refers to Questionnaire 1 responses, and 'time point 2' refers to Questionnaire 2 responses.

RQ3.1: Is there a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point?

This first analysis for RQ3 looked to see if respondents had the amount of alone-time that they wanted. Both questionnaires asked respondents to provide the daily average alone-time that they *had* over the past two weeks and the daily average alone-time that they *wanted* over the past two weeks:

"Q2: On average, over the past two weeks, approximately how much alone-time did you have each day? (This might not be the same every day, an average over the past two weeks is fine)."

"Q3: On average, over the past two weeks, how much alone-time did you want or need each day? (This might not be the same every day, an average over the past two weeks is fine)."

The first seven multiple choice items for Q2 and Q3 were provided as categories, from '0 hours' to '5-6 hours', and a text box was provided for respondents who selected 'more than 6 hours' to type in their own answer. If respondents added only one figure such as '9', I assumed that they meant at least 9 hours, e.g. '9' was treated as '9 to 10 hours'. With the additional assumption that most responders would have at least 6 hours of sleep in any 24-hour period, any categories added above 18 hours were treated as outliers and were not included in any of the following analyses (Chapter Five, Table 5.2). Additionally, text answers for 'more than 6 hours' in which the respondents had provided context without committing to a daily average were also discarded. After 6.4% of responses were removed as outliers or for unusable text responses, 247 responses were included.

Figure 6.1 compares the daily average alone-time hours *had* (dark grey), with the daily average alone-time hours *wanted* (light grey) as reported by respondents at time point 1. Although only two respondents wanted less than one daily average hour of alone-time (including no alone-time), this was the reality for 53 respondents. Meanwhile, the highest selected alone-time had, at 2-3 hours per day, falls just short of the highest selected alone-time wanted at 3-4 hours.

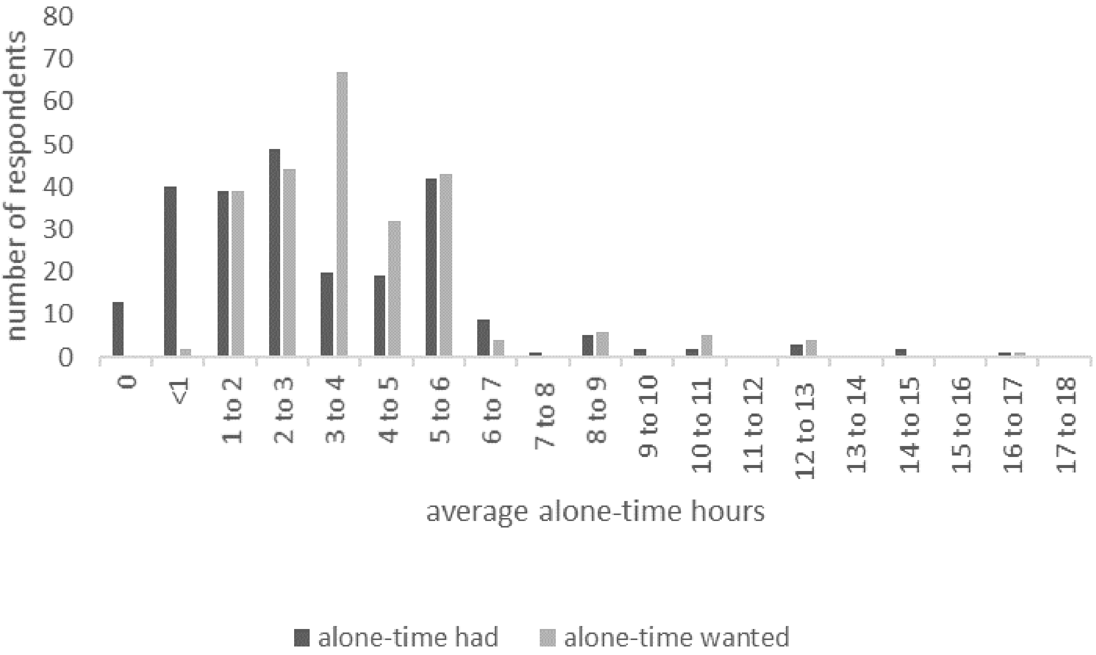

Figure 6.1: Average daily alone-time hours had and wanted at time point 1 (*n*=247).

Figure 6.2 shows the same comparison reported by respondents at time point 2. As shown in Chapter Five (Table 5.3), after 11.9% of responses were removed as outliers or for unusable text responses, 146 responses were included. Although Figure 6.2 represents 101 less responses than Figure 6.1, the bar charts show a similar distribution: while 0.8% of time point 1 respondents and 1.4% of time point 2 respondents wanted less than one hour of average daily alone-time; 21.5% of time point 1 respondents and 21.9% of time point 2 respondents had less than one hour of daily average alone-time. As for time point 1, the highest selected average daily alone-time hours wanted was 3-4, however, at time point 2 the highest selected average daily alone-time hours had was only 1-2.

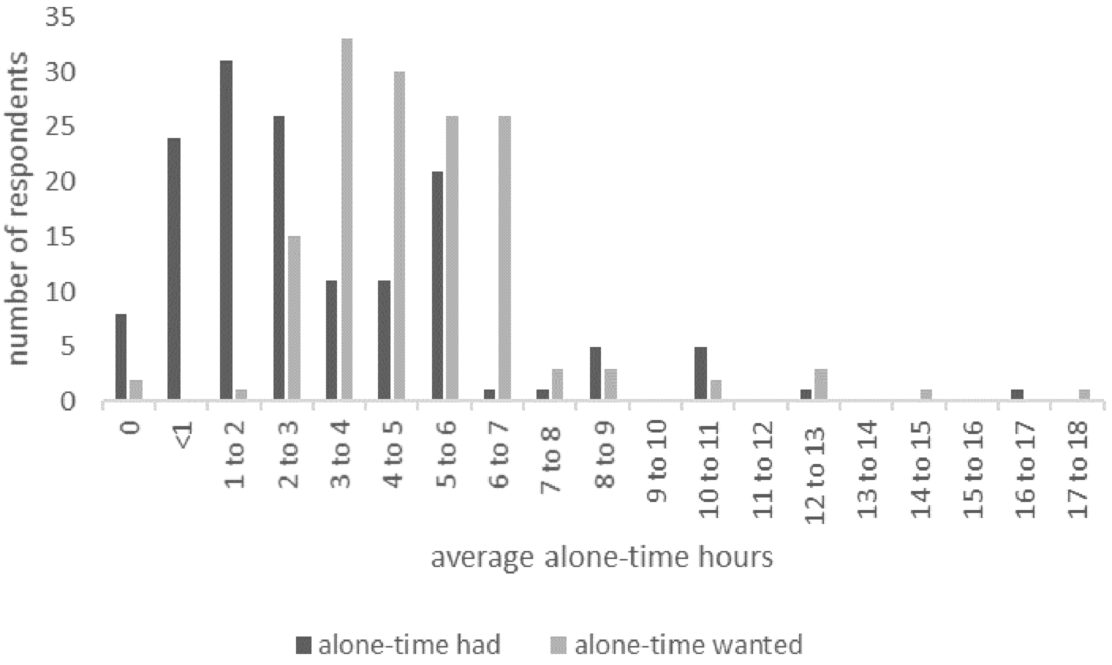

Figure 6.2: Average daily alone-time hours had and wanted at time point 2 (*n*=146).

Figures 6.3 and 6.4 show that at both time-points the difference between alone-time had and alone-time wanted (i.e. the exposure variable) is reasonably Normally distributed (an approximately bell-shaped curve with the greatest frequency of scores in the middle, and smaller frequencies towards the extremes).

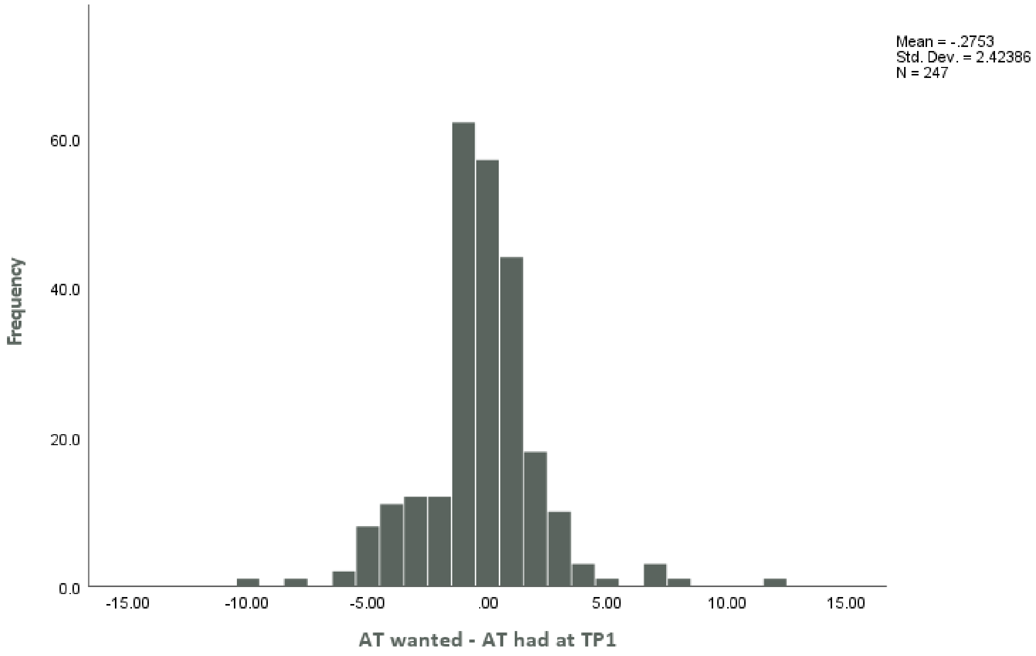

Figure 6.3: Histogram showing the distribution of difference between the amount of alone-time wanted and the amount of alone time that respondents had at time point 1.

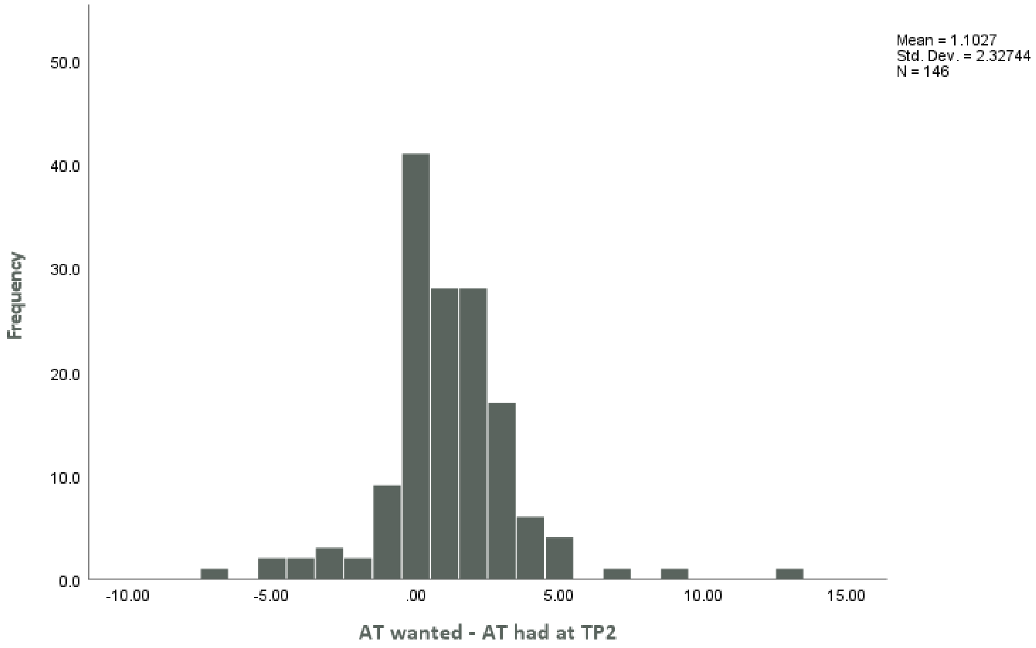

Figure 6.4: Histogram showing the distribution of difference between the amount of alone-time wanted and the amount of alone-time that respondents had at time point 2.

One-sample t-tests were used to test whether there were significant differences between the amount of alone-time had with the amount of alone-time wanted at each time point (please note that all SPSS outputs for statistical tests can be found in Appendix R). At time point 1 a two-sided *p*-value of 0.075 suggests no strong evidence of difference. A mean of -0.275 (confidence interval -0.579 to 0.029) suggests respondents had just over 15 minutes *more* daily average alone-time than was wanted). However, a two-sided *p*-value of 0.001 at time point 2 suggests evidence that respondents' alone-time had was significantly different to their alone-time wanted, i.e. that they had significantly less alone-time than they wanted. A mean of 1.103 (confidence interval 0.722 to 1.483) suggests that respondents had just over an hour *less* daily average alone-time than was wanted.

A sensitivity analysis repeated this test at time point 1, excluding all time point 1 responses which were not matched with time point 2 responses. There was still no strong evidence of difference: p = 0.674, n = 146.

RQ3.2: Is there a relationship between the difference between alone-time wanted and alone-time had at time point 1 with the change in wellbeing at both time points?

To measure the outcome variable, respondents were asked to complete the Warwick-Edinburgh Mental Well-being Scale (WEMWBS) at both time-points.

"Below are some statements about feelings and thoughts. Please select the answer that best describes your experience of each over the last 2 weeks. (Warwick–Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.)"

Figures 6.5 and 6.6 show that the frequency of the average wellbeing scores at each time point were reasonably Normally distributed. The scores were 39.5 at time point 1 (with a standard deviation of 8.7) and 39.4 at time point 2 (with a standard deviation of 9.3). The difference in sample size (discussed in Chapter Five) reflects the number of people who completed Questionnaire 1 but did not complete Questionnaire 2.

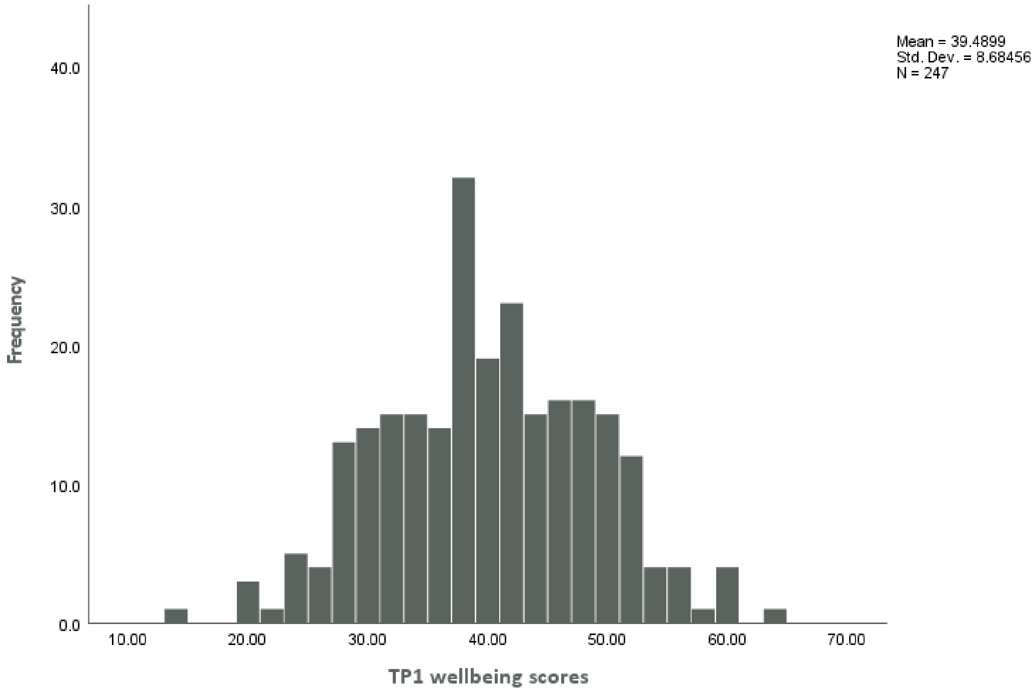

Figure 6.5: Histogram showing the distribution of wellbeing total scores at time point 1.

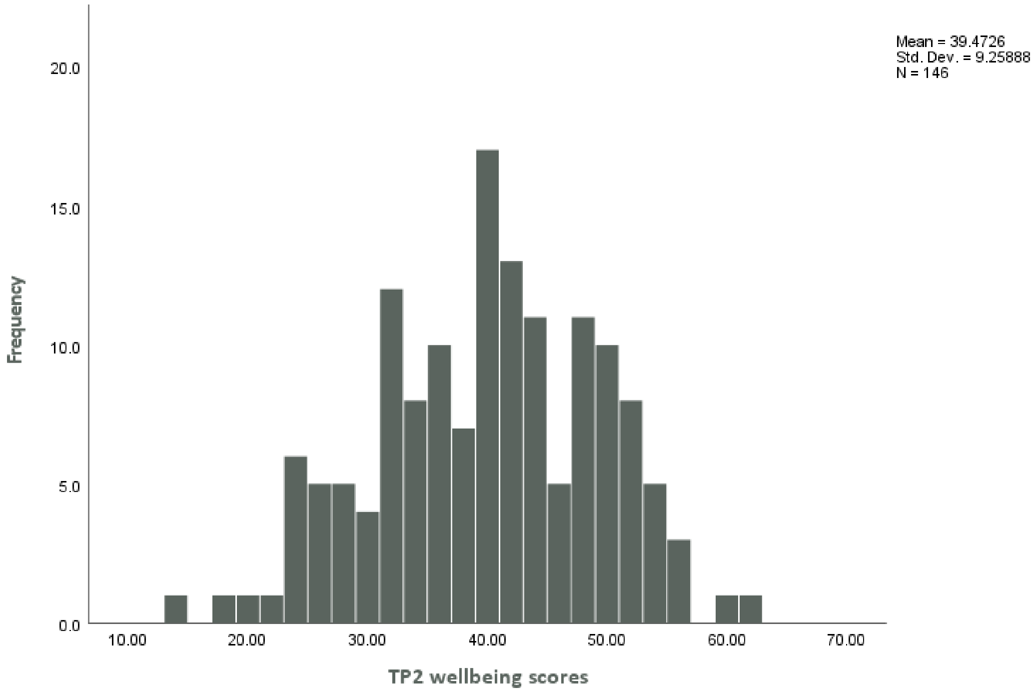

Figure 6.6: Histogram showing the distribution of wellbeing total scores at time point 2.

A scatterplot (Figure 6.7) and correlation analysis showed no evidence of a linear relationship between the exposure variable at time point 1 and the change in wellbeing between the two time points (*r* = 0.004, *p* = 0.960, confidence interval = -0.158 to 0.167).

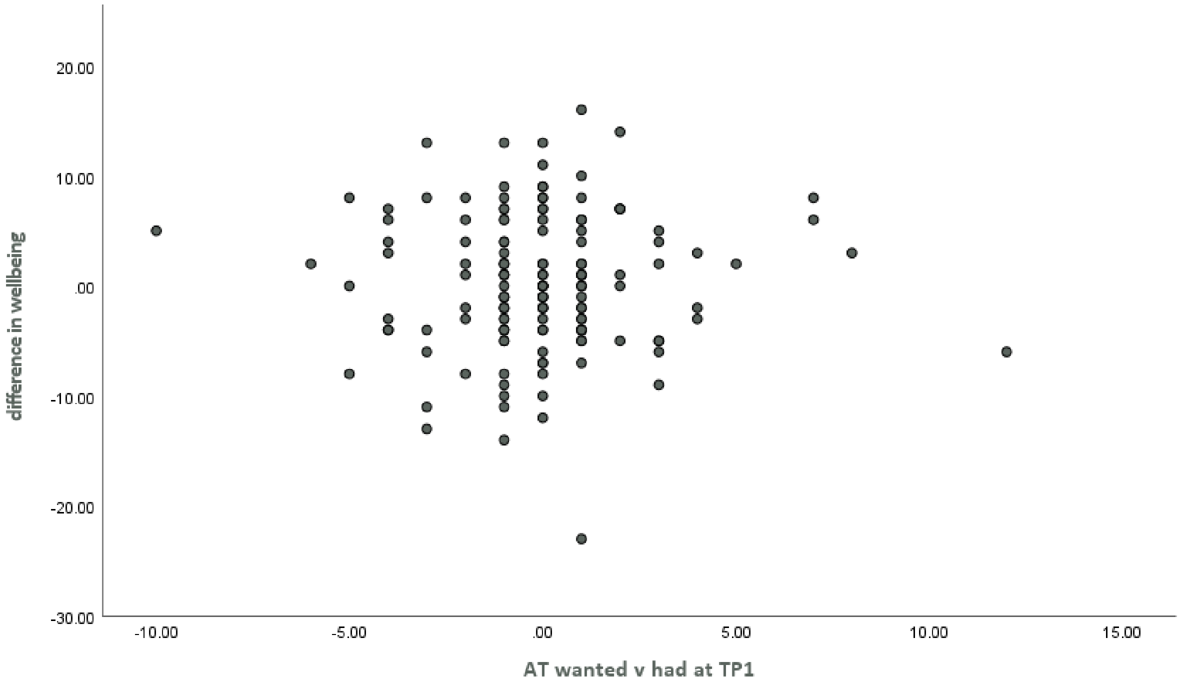

Figure 6.7: Scatterplot of difference between alone-time wanted and alone-time had at time point 1, with the change in wellbeing between both time points.

A sensitivity analysis was not necessary as this calculation already only included matched responses.

RQ3.3: Is there a relationship between the difference between alone-time wanted and alone-time had with wellbeing at the same time point?

At time point 1 there is no evidence of a relationship between alone-time wanted and alone-time had, with wellbeing. Neither a scatterplot (Figure 6.8), nor a Pearson’s correlation show any relationship between the exposure and outcome variables (*r* = -0.062, *p* = 0.335, *n* = 247).

A sensitivity analysis repeated this test, excluding all time point 1 responses which were not matched with time point 2 responses. There was still no evidence of a relationship between alone-time wanted and alone-time had, with wellbeing: *r* = -0.057, *p* = 0.492, *n* = 146.

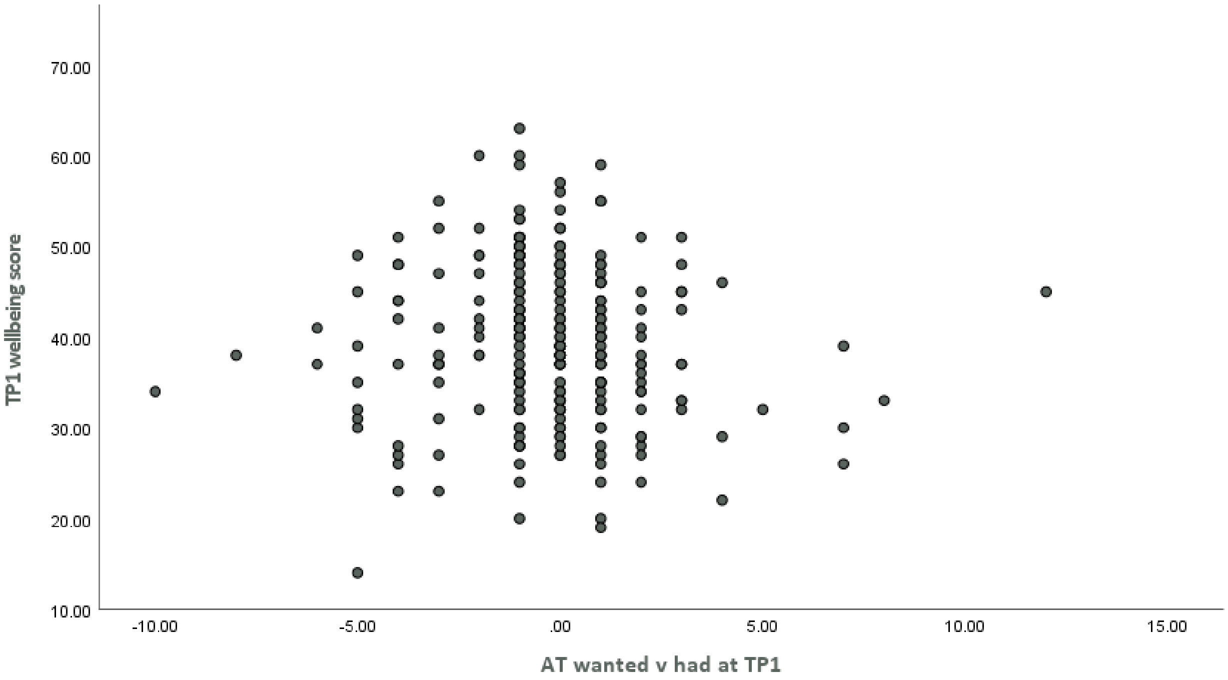

Figure 6.8: Scatterplot of difference between alone-time wanted and alone-time had at time point 1 with wellbeing at time point 1.

A scatterplot (Figure 6.9) did not appear to show any linear relationship between the exposure and outcome variables at time point 2. However, a Pearson's correlation showed evidence of a negative relationship between the variables at time point 2, indicating that respondents having at least the amount of alone-time they wanted was associated with higher wellbeing, whereas having less alone-time than wanted was associated with lower wellbeing (*r* = -0.218, *p* = 0.008, *n* = 146).

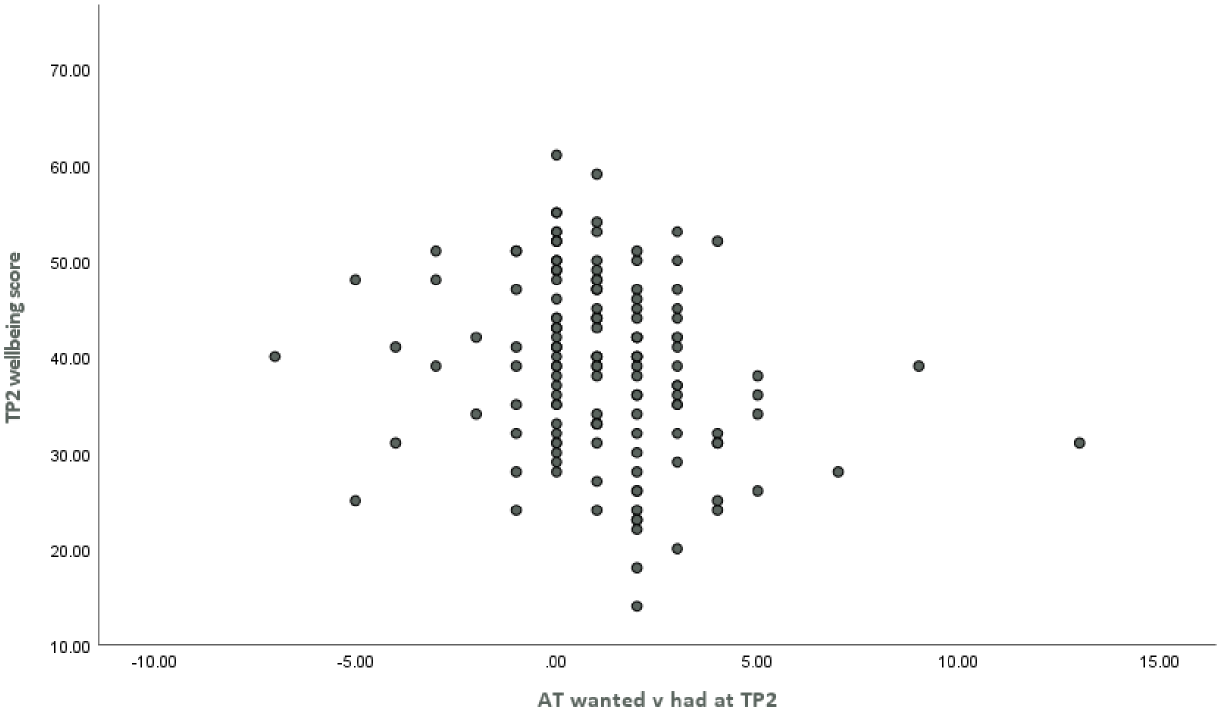

Figure 6.9: Scatterplot of difference between alone-time wanted and alone-time had at time point 2, with wellbeing at time point 2.

RQ3.4: Is there an association between the number of alone-time hours had at each time point, and wellbeing at the same time point?

Scatterplots (Figures 6.10 and 6.11) and Pearson's correlations showed no relationship between the number of alone-time hours had and wellbeing at the time point 1 (r = 0.008, p = 0.906, n = 247), or between the number of alone-time hours had and wellbeing at time point 2 (r = 0.107, p = 0.197, n = 146). As such, there was no evidence in this sample that the number of alone-time hours had is associated with wellbeing at the same time point.

A sensitivity analysis repeated this test, excluding all time point 1 responses which were not matched with time point 2 responses. There was still no relationship:
r = 0.093, p = 0.264, n = 146.

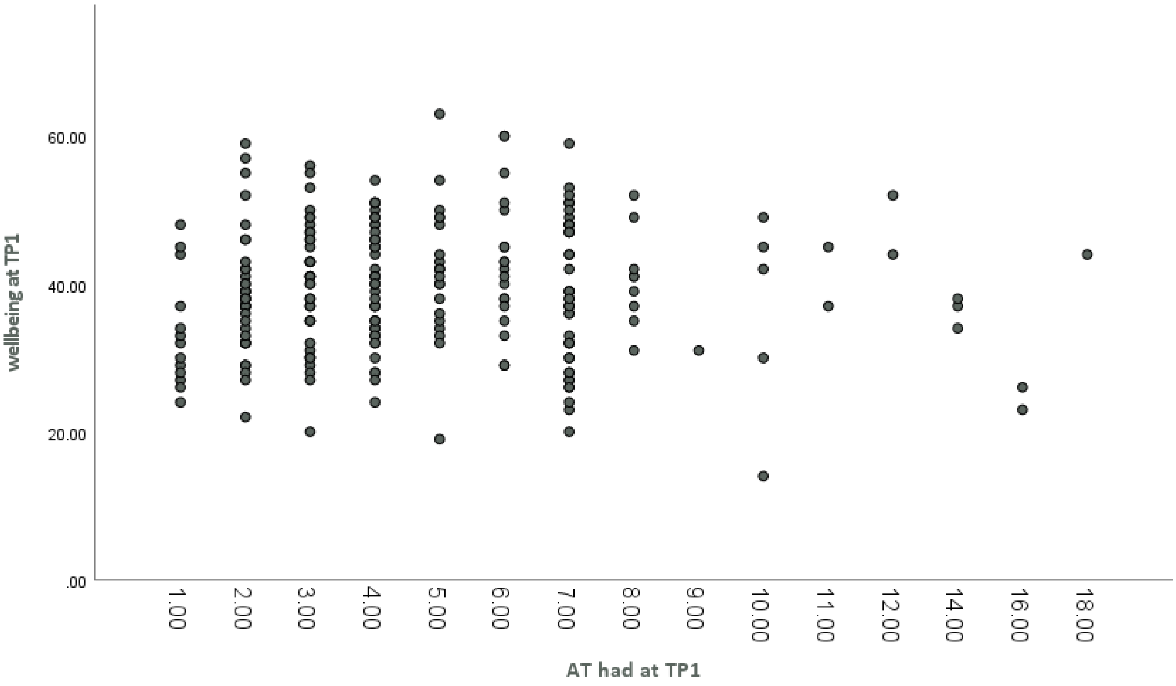

Figure 6.10: Scatterplot of alone-time had at time point 1, with wellbeing at time point 1.

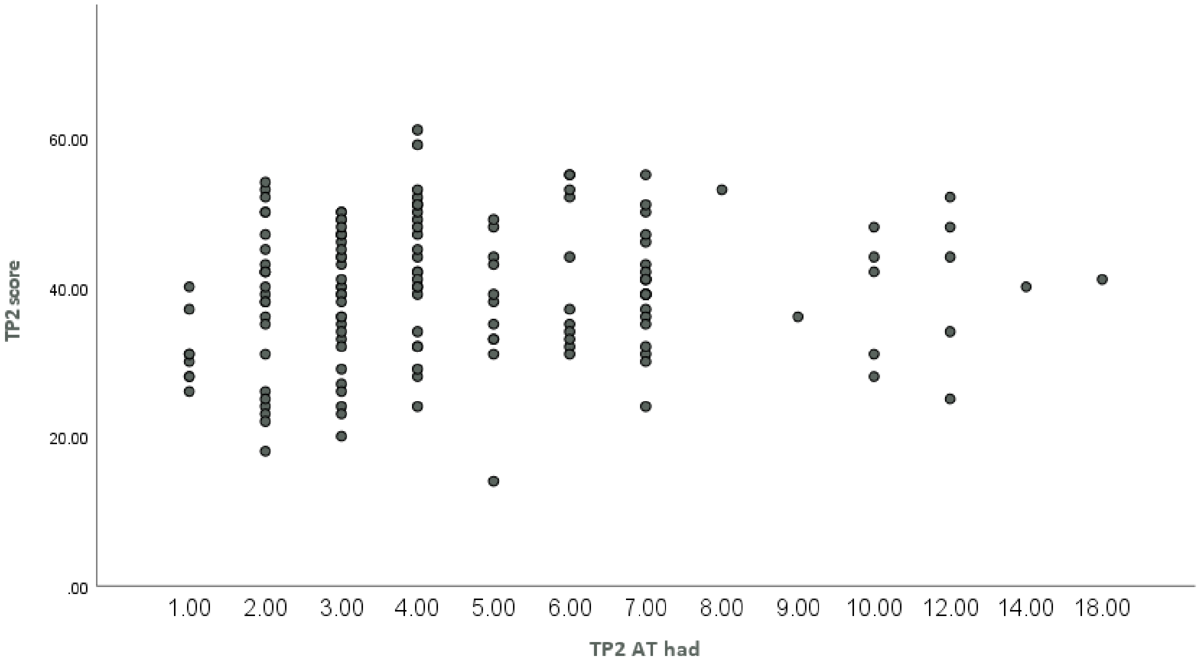

Figure 6.11: Scatterplot of alone-time had at time point 2, with wellbeing at time point 2.

RQ3.5: Is there an association with wellbeing at time point 1 and the number of alone-time hours wanted at time point 2?

The final analysis looked to see if there was any evidence of an association between wellbeing at time point 1 and the amount of alone-time wanted at time point 2. Neither a scatterplot (Figure 6.12) nor a Pearson's correlation (*r* = -0.032, *p* = 0.705, *n* = 146) show any relationship between these variables. This indicates that lower wellbeing at one time point does not necessarily mean that more alone-time might be wanted in the near future.

A sensitivity analysis repeating this test was not necessary as this calculation already only used matched responses.

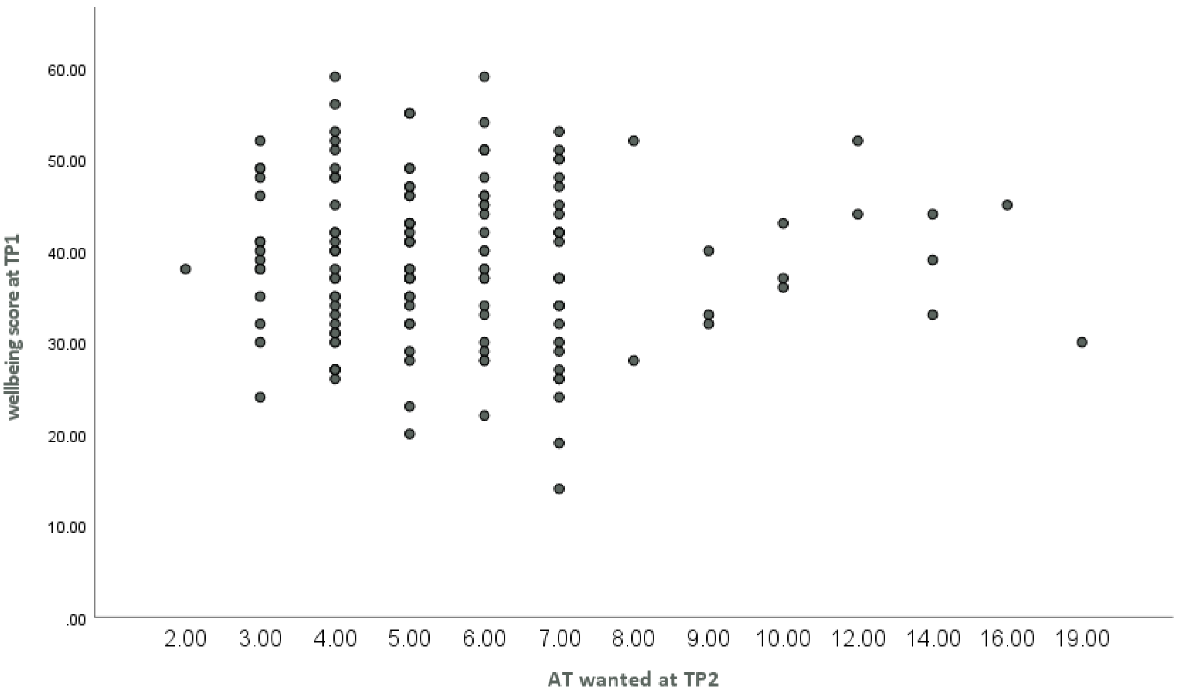

Figure 6.12: Scatterplot to show relationship between the wellbeing score at time point 1, with alone-time wanted at time point 2.

6.3 Discussion

How autistic adults prefer to spend alone-time

The results showed that autistic adults enjoy a range of alone-time activities, and that those enjoyed by the most respondents closely relate to the alone-time activities that the respondents feel are most important for improving or maintaining their wellbeing. Autistic adults and adolescents engage in alone-time activities more often than social activities, and more often than people who are not autistic (Stacey et al., 2019; Bishop-Fitzpatrick *et al*., 2017). Engaging in activities alone rather than with others, appears to moderate the relationship between perceived stress and quality of life for autistic adults, which is not the case with adults who are not autistic (Bishop-Fitzpatrick *et al*., 2017; Smith *et al*., 2019). However, until the current study, little research to date has recorded which alone-time activities are preferred by autistic adults for enjoyment and wellbeing. This may reflect a research bias which sees autistic people's engagement in leisure activities, particularly social leisure activities, in terms of social skills interventions. For instance, Parenteau's *et al*. (2023) survey of autistic adults about their leisure time concludes that, as social partners and social interaction were the highest reported under an "unhappy" domain, social skills teaching might enable autistic adults to build positive relationships and manage conflict. This type of research does not consider the role that sensory and social environments play in supporting or creating barriers for autistic adults' social engagement, let alone that solitary activities should not be seen as less desirable for wellbeing than social activities.

The most popular alone-time activity by far was "Read, watch TV or films, listen to audio books, podcasts, music or the radio etc.", followed by "Social media" and "Study an area of interest (books, papers, online etc.)". In terms of popularity these activities are followed by "Indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc." and "Napping or being still". There appears to be little difference between autistic people and people who are not autistic when comparing solitary activities such as listening to music, being online, being creative, and watching TV (Stacey *et al*. 2019). However, autistic people engage with intense interests more than people who are not autistic (Bishop-Fitzpatrick *et al*., 2017). While many of the activity categories in the current study could be considered in the context of an intense interest, the specific item "Study an area of interest (books, papers, online etc.)" was the third most popular activity, and was considered the sixth most important activity for wellbeing. For autistic adults, engaging with an intense area of interest is calming, positive and reduces anxiety (Koenig & Hough Williams 2017), and autistic adults with one or more intense interests (including autism, computers, music, and nature and gardening) enjoy leisure more than those who don't (Grove *et al.*, 2018). As discussed in Chapter Four, this positive relationship with intense interests reframes the DSM's deficit-based criteria and suggests that engaging with intense interests should be further explored in the context of monotropism and autistic wellbeing.

In terms of categories which respondents felt to be the most important for their wellbeing, there were a few items of particular interest. For instance, "Napping or being still" was the second highest endorsed option. Given that the qualitative participants discussed exhaustion from social and sensory input, and that recent literature suggests exhaustion as a key feature of autistic burnout (Raymaker *et al.,* 2020; Higgins *et al.,* 2021; Mantzalas *et al*. 2021), napping would seem to be a highly necessary alone-time option for wellbeing. Just over half of the participants selected napping or being still as something they like to do in their alone-time. Secondly, gaming (as discussed in Chapter Four) was the fifth most selected option as being important for wellbeing, an activity which, in contrast to previous research concerned with potential harms of gaming (e.g. Sarfraz *et al*., 2023), has only recently been identified as having possible wellbeing benefits for autistic people (Cheak-Zamora & Odunleye, 2022; Pavlopoulou *et al*., 2022). Finally, stimming (previously discussed in Chapter Two), which 36.3% of the respondents enjoyed during alone-time, was considered to be the most important alone-time activity by 3.4% of the respondents. While this may appear a small number, it is interesting because although qualitative research has previously identified the benefits of stimming in regulating social and sensory overload (Kapp *et al*., 2019), it does not appear to have been recorded in quantitative wellbeing literature to date.

Where autistic adults choose to spend alone-time

While the negative effects of certain sensory inputs on autistic people is well documented, particularly negative sensory input, there is very little in the literature that asks what autistic people want and need from the sensory environments that they spend time in. The current study appears to be the first time that autistic adults have been asked where they prefer to spend alone-time, and which environmental considerations support their wellbeing during this time. The respondents' environmental requirements for alone-time were varied, but suggest particular preferences and wellbeing needs for indoor spaces where they had control over the sensory environment and that felt safe and cosy; and/or remote and natural outdoor spaces. Although these preferences were specifically around alone-time, they relate to research by MacLennan *et al*. (2022b) into autistic adult's sensory experiences of public places to describe what aspects make an environment more or less disabling for autistic adults; of the six identified principles, three (recovery, 'sensoryscape' and space) are particularly relevant to the most-popular environment categories in the current study. For instance, subthemes of 'sensoryscape' - (1) sensory burden, (2) sustained and inescapable input, and (3) uncontrollable environment - highlight how important it is for autistic people to be able to moderate the strength and range of sensory input. Meanwhile the principle 'recovery' which describes the need for places to escape, recover and prepare, is reflected in the current study's participants' need for safe and cosy spaces.

"Outdoor spaces where there are no or very few people nearby" and "natural or rural outdoor space" were the two highest selected options both for outdoor spaces that respondents like to spend their alone time in, and for outdoor spaces considered to be most important for wellbeing. These relate to MacLennan's *et al*. (2022b) subthemes of 'space' - (1) busy and crowded, and (2) confined built environment - which describe how close and confined public spaces can be exceptionally challenging. However, it is important to remember the heterogeneity of the autistic population. Friedman *et al*. (2023) found that while most of their 127 autistic participants had a positive relationship with natural spaces, six associated nature with increased anxiety and sensory issues, and a further five had neutral responses to how natural spaces impacted their mental health. This heterogeneity is also reflected in the contrast between the three of 16 qualitative participants who described their love of urban or street photography, and only 17 of 267 quantitative respondents who reported enjoying spending their alone-time in urban spaces.

These findings around where autistic people enjoy spending alone-time and the identification of which alone-time spaces are felt to be important for wellbeing, have implications for interventions designed to improve autistic people's mental health. A good example can be found in work by the National Development Team for Inclusion (NDTi). The effect of sensory experiences is at the forefront of their autistic-led recommendations for autistic young people's inpatient services (NDTi, 2020a) which include the sensory considerations: 'creating a predictable environment', 'reduce noise and echo', 'consider the impact of lighting and support user control', 'consider the impact of smells'', and 'consider the impact of touch and texture'. The report also highlights the need for access to personal spaces which young people have some control over and can thus relax and regulate in. NDTi has also published a report on supporting autistic adults in supported housing, which again highlights the need for space to self-manage and self-regulate (NDTi, 2020b). The authors, a neurodiverse team of academics and service users, also draw attention to an 'autistic pattern' of intensive work periods interspersed with downtime which may include quiet time, resting or engaging with a favourite activity; most likely this downtime would necessitate access to the types of spaces described in the current study. The current research findings support the NDTi recommendations in the importance of not only the need for alone-time, but the need for indoor environments where the individual has control over sensory input.

Alone-time hours and wellbeing

To my knowledge, this is the first time that anyone has collected data comparing the number of alone-time hours autistic people have with the number of alone-time hours autistic people want. Although I expected that respondents would have significantly less alone-time than they wanted, there was no evidence to support this at time point 1. However, there was strong evidence of a daily deficit at time point 2. It would be difficult to know with any certainty why there is a difference between the time points, but a possible explanation is that respondents may have read this question differently at time point 2: prior awareness of the questions being asked may have created participant bias.

The WEMWBS data is potentially concerning. The minimum possible WEMWBS score is 14 and the maximum is 70; although the WEMWBS is not designed to measure depression, the user-guide suggests that people who score ≤40 could be at high risk of major depression. The current study's respondent WEMWBS scores averaged at 39.5 at time point 1 (*n* = 247, *SD* = 8.6) and also at time point 2 (*n* = 146, *SD* = 9.3). These scores, which are similar to Muniandy's *et al*. (2021) average autistic respondent score of 40.7 (*n* = 73, *SD* = 10.1), support a body of research that indicates a high risk of depression for autistic people

(Fombonne *et al*., 2020; Hand *et al*., 2020; Croen *et al*., 2015). For comparison, the mean score for the Scottish population since 2008 has varied between 50.0 and 49.7 (Scottish Health Survey), and the mean score for the English population has varied between 50.9 and 52.3 since 2010 (Health Survey for England). However, it is important to remember that, as the WEMWBS has not been validated for autistic people, some items may be interpreted differently by autistic people (Stacey & Cage, 2022; Jones, 2022). For instance, one of the test participants gave the feedback that item 4 "I've been feeling interested in other people" - should not be included as they didn't feel that being interested in other people had any bearing on their wellbeing. Without wellbeing measures which have been specifically validated for autistic people, it is difficult to draw definite conclusions around autistic wellbeing compared with non-autistic wellbeing (Pellicano & Heyworth, 2023).

There was limited evidence in the data to suggest that having more or less alone-time than was wanted had any relationship with wellbeing, either in longitudinal or cross-sectional analyses. Additional analyses designed to look for relationships between whether higher alone-time correlated with higher wellbeing, or whether higher wellbeing correlated with wanting or needing less alone-time also lacked evidence to suggest correlations. While it is disappointing not to have statistically significant findings in this area, it does suggest that further qualitative or participatory work should be done to find more useful ways to frame hypotheses around the potential for alone-time to benefit wellbeing, or whether a different quantitative outcome measure might elicit different responses. This is discussed further in the following two chapters.

6.4 Interpreting the integration of findings

Mixed methods research involves not just collecting and analysing both qualitative and quantitative data, but integrating the findings, and interpreting this integration (Tashakkori & Creswell, 2007). I now discuss the integration of these phases, while referring to Plano Clark and Ivankova's (2016) five rationales for mixed methods research (previously described in Chapter Five): offsetting strengths and weaknesses, triangulation, complementarity, development and social justice.

In Chapter One I outlined how I designed my PhD research to explore the previously under-researched phenomenon of self-managed time and space alone as a wellbeing strategy for autistic people. As a frequent need for time alone was already commonly discussed within the autistic community, but not yet addressed in the literature, I felt that it was important to gain an in-depth understanding, not just of *how* and *where* autistic people choose to spend time alone, but *why* they choose to spend time alone. Without previous theoretical or empirical research identifying the *why*, it would have been, at best, difficult to gain generalisable findings about the *how* and *where* and, at worst, epistemically unsound to create quantitative measures from purely observational understandings, or understandings based on non-autistic populations. Neither would this research have epistemic integrity had generalisability been assumed from such a small subset of the autistic adult population; the value of qualitative data lies in the depth of understanding gleaned from subjective or intersubjective interpretations rather than definitive, quantifiable results. An exploratory sequential mixed-methods design enabled me to *offset strengths and weaknesses* of purely qualitative and purely quantitative methodologies. Taking an intersubjective viewpoint enabled me to connect inductive-led data with deductive-led theory through building the quantitative feature from rich qualitative data.

The four qualitative themes primarily answered the *why* of the overall research aim. The participants described the overwhelm resulting from social and sensory input from social environments, the necessity of spaces to retreat to, the regulatory effects of immersive activities, and ways of reducing future overwhelm when engaging in desired social activities. These four themes helped to describe what appeared to be a daily reality for the participants, a constant striving to navigate and moderate a delicate balance between experiencing disabling overwhelm and engaging in desirable and/or necessary social interaction. The overall thematic story also highlighted a need for autonomy: the wherewithal to create and access individualised sensory sanctuaries, and engage in preferred regulatory activities. These individual themes and the thematic story answered the research aim with rich context which described the participants lived-experiences and relationships with their own conceptualisations of alone-time.

While the themes themselves did not answer the *how* and *where* of the research aim in terms of preferred activities and environments, the qualitative data helped to inform the survey questions, thus covering Plano Clark and Ivankova's *development* rationale. Grouping certain activities together, such as "Gentle outdoor recreation such as sitting in nature, slow walking etc.” were considered in terms of retreat from social environments, while “Outdoor creative activity such as gardening, drawing, photography etc.” had been discussed in terms of immersion in outdoor environments. “Indoor spaces that are interesting for your senses (visuals, music, scents etc.)” was not a category I would have thought to include were it not for some of the participants describing how their retreat spaces needed to inspire their senses rather than reduce sensory input. Similarly, I would not have considered “Urban spaces (such as city streets or busy shopping areas)” had some of the participants not discussed street photography as a solitary activity. Without using the qualitative data to inform the *how* and *where* questionnaire items, the descriptive findings would have lacked validity: they would not have been relevant to the population studied. As such*, triangulation* - comparing the qualitative and quantitative results for convergence and divergence - was not an appropriate rationale. Rather, *complementarity* - using the results from both qualitative and quantitative results to learn about different facets of the phenomenon - was obtained through both contextual and generalisable understandings of *how* autistic adults choose to spend their alone-time, and *where* they choose to spend their alone-time.

The exploratory sequential nature of the research design also allowed for engagement with the qualitative data to inform a key change in the research aim, that of changing the research aim’s focus on anxiety to wellbeing. This change, based on participant data and direct input from the CAG, reflected autistic people’s epistemic agency over the research as a whole. Stubbornly continuing with a focus on anxiety, when the participants had not mentioned anxiety in their interviews but had instead chosen to discuss wellbeing benefits, would have been epistemically unjust. This adherence to epistemic agency aligns with a *social justice* perspective in that it involves and includes marginalised voices in creating and using knowledge about themselves.

Chapter conclusion

I have now separately presented and discussed the qualitative and quantitative findings, and discussed the integration of the findings from both phases. The following chapter discusses the considerations and development of community outputs: the recommendations arising from this work as developed with the community advisory group, my own suggestions for how the qualitative themes might be used to support autistic wellbeing in various contexts, and ethical dissemination of the research findings.

Chapter Seven: Community Outputs, Recommendations and Dissemination

> Attempting to understand Autistic people and culture is difficult for many, because of the chasm between a) the pseudo-scientific and culturally biased behaviourist framing of autism in the DSM and b) accounts of Autistic ways of being articulated in the neurodiversity paradigm.
>
> - *Jorn Bettin (2022), autistic researcher (via twitter).*

Traditionally, future research, policy, and practice recommendations are presented and discussed in the final chapter of a thesis; in this way the recommendations are shown to be based on a synthesis of the entire PhD. However, as outlined in Chapter Three (Figure 3.1), recommendations arising from the current study were developed with the CAG and so are part of the overall study design. This distinction is important; as discussed in Chapter Two, community input into identifying autistic mental health and wellbeing research priorities has only recently been considered in autism research. When autism is understood as it is experienced by autistic people, rather than how it is observed by people who are not autistic, there is a greater opportunity to re-evaluate what improving autistic wellbeing means for autistic people, and ascertain what wellbeing itself means for autistic people.

This penultimate chapter discusses outputs arising from my PhD research: (1) the recommendations developed with the CAG, (2) suggestions for practice based on my qualitative findings and a discussion of how these suggestions might have impacted three previously documented cases of autistic people in acute mental-health care environments and, (3) considerations around ongoing dissemination of my research. I believe that these outputs show a commitment to ethical research through (1) including other stakeholders' (i.e. other autistic adults') interpretations of how the findings might impact future autistic wellbeing work; (2) considering how the findings might impact autistic adults who are not in a position to easily able to advocate for themselves, and (3) considering the impact of respectful and inclusive dissemination of the findings.

7.1 Recommendations for research, policy and practice

I reflect on the process of working with the CAG in Chapter Eight, but here present and then discuss the group's recommendations in answer to my summarised qualitative and quantitative findings.

Developing the community advisory group recommendations

After integrating the qualitative and quantitative findings (see previous chapter), I emailed a summary to the CAG. Two weeks later we met online as a group to discuss insights from the findings and brainstorm ideas for recommendations. Prior to the meeting I shared an online document with the headings 'policy', 'practice' and 'research' so that members could add ideas during the meeting and then asynchronously access, discuss and edit recommendations during a four-week period following the meeting.

The group had two key concerns about the study findings. The first concern was that, considering there was no evidence for RQ3 (i.e. there did not appear to be a clear association between average alone-time hours *had*, alone-time hours *wanted*, or the difference between these, with wellbeing), not enough qualitative work had been done to establish what alone-time might mean for different groups of autistic people, such as people who did or didn't live alone, and people with or without caring responsibilities. Their second concern was that the quantitative study's respondent demographic was narrow, and therefore the findings may not be reflective of the autistic adult population of the UK. As such, the group prioritised recommendations for increasing representativeness in qualitative research (increasing representativeness in quantitative methods was not discussed by the group but is addressed in Chapter Eight). The policy and practice recommendations reflect what stood out to the CAG members from my findings, and so are almost entirely focussed on the second qualitative theme: *retreating from social and sensory distraction*. This theme was considered in terms of being adaptable to different settings such as workplaces, hospitals, universities and the home. Later in this chapter I offer suggestions for how the other qualitative themes might also be used to support autistic wellbeing in various settings.

Community advisory group recommendations

Here I present the CAG's recommendations for research, policy and practice, before discussing the recommendations. It should be noted that we did not search for existing recommendations in advance; these were created solely from the group members' individual and collective interpretations of my findings. Thus, some may mirror existing policy and practice guidelines, and research recommendations.

Research

- Further qualitative research could improve understandings of what alone-time means for autistic adults from different demographics, including those with differing living arrangements (living with/without friends or family), people who do/don't use social media, people who are/aren't employed, and people with/without caring responsibilities.
- Creative methods could be used to find out what alone-time means for previously under-represented groups of autistic participants, including those who do not have access to computers and/or use social media.
- Once qualitative methods have more fully explored and defined what alone-time means for a heterogeneous sample of autistic people, quantitative work may be more effective in assessing how alone-time affects wellbeing outcomes.
- Future research could focus on two separate aspects of alone-time (1) retreating from social and sensory overwhelm, (2) regulating through immersive activities.
- Future research could focus on wellbeing benefits of designated quiet spaces in workplaces, universities, public settings etc., and whether wellbeing benefits differ according to whether these spaces are accessed alone, or with other people. Similar research could also compare samples of autistic and non-autistic people who are experiencing work-stress.
- Future research could assess whether autistic people have difficulties accessing alone-time outdoors, and should focus on how gender, ethnicity, co-occurring conditions, financial situations, location etc. may further impact access.

Policy

- In line with the Equality Act 2010, flexible working should be considered as a reasonable adjustment and embraced by workplace culture to take account of autistic employees' need for time alone, respite and other support needs, and enable wellbeing and productivity for autistic staff.
- The need for and provision of quiet spaces due to their wellbeing benefits should be embedded in wellbeing policies for workplaces, public spaces, hospitals and education buildings.
- In line with the British Standards Institution guidance for quiet and restorative spaces for neurodivergent people (PAS 6463), sensory considerations for these rooms should be designed and regularly reassessed with input from autistic people.
- Workplace environments should provide work areas for monotropic thinkers, i.e. without sensory and social distractions.
- The above policies should be incorporated into support policies for those working at home, including at-home Carers.

Practice

- Employers should understand that autistic people may need to access quiet spaces to recover from sensory and social overload and/or to fully immerse themselves in their work. As such, provision should be made for quiet spaces which accommodate these needs.
- Employers should emphasise the importance of designated quiet spaces in the workplace and within workplace culture. Use of these spaces, and/or working from home should not only be considered a reasonable adjustment for autistic people but supported and actively encouraged.
- Employers should be aware of the heterogeneity of autistic people, and that sensory accommodations for quiet spaces should be informed by those who might need to access them.
- Access to alone-time should be written into Carers' Needs Assessments, particularly where Carer and Cared-for live together and care needs are high. Assessors and

decision makers should receive training on the importance of access to alone-time, and to understand the impacts of not providing this.

Discussion of community advisory group recommendations

The CAG recommended that, given the heterogeneity of the autistic population, further qualitative research should aim to garner more nuanced conceptual understandings of what alone-time means to different groups of autistic people, before attempting to reassess quantitative associations between alone-time and autistic wellbeing. Research could, for instance, seek to compare what alone-time might mean for people who live alone or live with friends or family; people with or without caring responsibilities, and people who go out to work, work from home or do not work. Additionally, the CAG was interested in how different groups of autistic people might be impacted by a lack of access to alone-time, particularly access to alone-time outdoors. Given that the current study was unable to evidence an association between the amount of alone-time had and wanted with wellbeing, widened understandings about the benefits of alone-time to wellbeing, and access to alone-time, may be vital to generate more accurate hypotheses and establish more generalisable quantitative measures to measure associations in future research.

Creative arts-based methods were suggested as a way of learning more about what alone-time means for autistic people who are not usually represented in autism research. Methods such as photography, dance, storytelling and creating textile art are sometimes incorporated within community based participatory research with marginalised communities but, to date, creative methods have very rarely been used in autism wellbeing studies. The few exceptions include a Photovoice project for which young autistic people took photos and then met weekly to discuss their photos and share their ideas about wellbeing (Lam *et al.*, 2020), and a study which offered multiple ways to engage as a participant, including narrative diaries and/or collages to share experiences of service provision (Ridout, 2017). As discussed in Chapter Two, until recently, most research about autistic mental health and wellbeing was based on secondary data, such as clinical records; since then, qualitative research has predominantly utilised interviews and focus groups (i.e. data collection via spoken word). Creative methods could offer unique perspectives on autistic wellbeing, particularly with participants who may have pragmatic speech difficulties, experience alexithymia (a difficulty in recognising or describing emotions), and/or find talking about their experiences challenging or emotionally triggering. Additionally, creative methods may be more fully inclusive of autistic people's communicative and narrative expressions (Ridout, 2017).

Two separate aspects of alone-time were identified during the qualitative analysis: retreating from social and sensory overwhelm, and regulating through immersive activities. Focussed research into either one of these aspects may provide further insights into how alone-time may benefit autistic mental health and wellbeing. Research which further explores how and why autistic people retreat from social and sensory overwhelm could answer questions about how to reduce this need through reducing overwhelm, and how to support this need through the provision of accessible, safe and destigmatised time and space to retreat. Research exploring how autistic people might regulate through immersive activities could consider the range of solitary activities chosen by autistic people, and measure the effectiveness of immersive processes in emotional and physical regulation. Similarly, future research could develop models to understand the psychological processes that link autonomous alone-time and immersive activities with regulating overwhelm and/or experiencing wellbeing.

A key element of the combined recommendations is that autonomy, over how and where alone-time is spent, is paramount. This is in line with autistic community research priorities which value self-initiated and self-managed strategies which do not require gatekeepers to allow access and do not seek to change characteristics of autistic identity (Benevides *et al.*, 2020b). In particular the CAG agreed that (1) quiet spaces should be widely accessible, both for emergencies and for proactively reducing social and sensory input to support wellbeing; and that (2) the design of these spaces should be reviewed by autistic users to ensure suitability and appropriateness for use. The group drew comparisons with multi-faith rooms which are commonly designed to accommodate multiple faith and personal needs for prayer or contemplation. They also recommended that further research might compare the benefits of quiet spaces which might be used by more than one person at a time, with spaces which could only be accessed by one person at a time; and that this same research could compare these results with results from a sample of non-autistic participants.

The CAG's policy and practice recommendations reflect the findings of a scoping review synthesising the literature on the built environment for autistic peoples with recommendations for designers, policy makers and clinicians (Black *et al*., 2022). The recommendations in the literature, which include reducing negatively experienced social and sensory input, and providing withdrawal or sensory spaces, also highlight the necessity of consulting with autistic people in the design of built environments. In terms of existing good practice, ASPECTSS Architecture for Autism (Mostafa, 2015) have now completed several projects sensitive to their criteria of acoustics, spatial sequencing, escape space, compartmentalisation, transitions, sensory zoning and safety; which together reduce sensory and cognitive load, and provide respite areas which are user-customisable. The aspect of ‘escape space’ is particularly important here, an acknowledgement that even with attention to reducing overload, a need to access a customisable space alone may still be necessary. Similarly, the British Standards Institution (2022) has recently created excellent and comprehensive guidance, PAS6463, on designing the built environment with neurodivergent people in mind, including detailed design considerations for quiet or restorative spaces to facilitate recovery from extreme stress or sensory overload. Guidance for these spaces is designed for mainstream settings and stresses flexibility for the user to adapt sensory aspects according to need and preference. Hopefully built environment recommendations which increase accessibility and reduce disability for autistic people will become more widely used in the future.

The policy and practice recommendations have particular implications for the workplace, although the CAG suggested that these same recommendations might also be adaptable for other environments such as hospitals or schools. The National Institute for Health and Care Excellence (NICE) guidelines (2022) for mental wellbeing at work recommend that policies, processes, and ways of working with staff should encourage fair and supportive work environments; however, they make no mention of the impact of sensory environments or social expectations. According to the Office of National Statistics, only 29% of autistic adults are employed (Office of National Statistics, 2021); autistic people find that workplace environments are inaccessible due to unsupportive social expectations and sensory input (Hayward *et al*., 2020). Future research might explore whether the following encourage enhance work outcomes for autistic people such as increased occupational wellbeing and higher rates of employment:

1. policies which increase accessibility for autistic people through reduced sensory and social overwhelm
2. provision of suitable and easily accessible escape places
3. policies which support monotropic thinking through social and sensory environmental considerations (i.e. work environments supporting monotropic focus by reducing social and sensory distractions)

The CAG pointed out that autistic people with caring responsibilities, particularly those who care for family members and so may find it difficult to access alone-time, should have their alone-time needs recognised, and that the implications of not being able to access alone-time should be built into support policies.

Additional recommended strategies to support wellbeing in various settings

Here I present possible strategies to support wellbeing based on my qualitative findings, before briefly discussing how these strategies could have been used in three previously documented cases of autistic people in acute mental-health care environments.

The policy and practice recommendations above were co-created with the CAG in the last few months of my PhD. They were based on the integrated findings of the qualitative and quantitative studies, and reflect the group's combined personal and professional interests in the study findings. As such, they were largely focussed on the provision of quiet rooms, in which autistic people could either retreat from sensory and social overwhelm, or in which social and sensory distractions might be minimised to encourage focussed work. Earlier in my research, on completion of the qualitative findings, I had drawn up a table of practical suggestions for self-support, the workplace, and care settings, based on each of the qualitative themes (Table 7.1). I include it here because, while several of these suggestions are already evident in the CAG recommendations (particularly those responding to Theme 2: *retreating from social and sensory overwhelm*) some stand alone in aiming to reduce overwhelm by supporting immersive activities, and forms of social engagement that are less likely to cause overwhelm.

Table 7.8: Practical suggestions for supporting autistic wellbeing in various settings.

	Self-support	**Employment**	**Care settings**
Reacting to social and sensory overwhelm	Appreciate that social and sensory input can be disabling, and that attempts to push through will come at a cost.	Appreciate that social and sensory input can be disabling.	Understand that social and sensory input can be disabling.
	Understand the pressures around, and impacts of social masking.	Understand the pressures around and impacts of social masking.	Understand the pressures around and impacts of social masking.
		Change the sensory environment where necessary, with input from those affected by it.	Change the sensory environment where necessary, with input from those affected by it.
		Reduce pressure to engage socially.	Reduce pressure to engage socially.
	Recognise signs of overwhelm and plan accordingly (e.g. find quiet spaces in advance).	Recognise signs of overwhelm and plan accordingly (e.g. provide quiet spaces).	Recognise signs of overwhelm and plan accordingly (e.g. provide quiet spaces).
	Create a sensory toolkit such as headphones and sunglasses	Accommodate needs for sensory tools such as headphones and sunglasses.	Accommodate needs for sensory tools such as headphones and sunglasses.
		Provide accommodations for those who find verbal communication difficult.	Provide accommodations for those who find verbal communication difficult.
		Provide options for working from home, where possible.	
Retreating from social and sensory overwhelm	Understand the necessity of easy access to 'safe' or 'sanctuary' spaces.	Understand the necessity of providing 'safe' or 'sanctuary' spaces.	Understand the necessity of providing 'safe' or 'sanctuary' spaces.
	Create 'sanctuary' spaces and plan accesses to these spaces.	Design 'sanctuary' spaces with user-input and plan access to these spaces.	Design 'sanctuary' spaces with user-input and plan access to these spaces.

	Ask for these spaces from employment or public spaces where possible.	Remove barriers and/or stigma to these spaces.	Remove barriers and/or stigma to these spaces
		Signpost these spaces.	Signpost these spaces.
Regulating, recovering and recharging	Understand that engaging with intense interests is a necessary tool for wellbeing.	Understand that engaging with intense interests is a necessary tool for wellbeing.	Understand that engaging with intense interests is a necessary tool for wellbeing.
	Create or obtain space/tools etc for engaging with intense interests.	Understand that engaging with intense interests may include work activities.	
		Remove barriers and/or stigma around this engagement.	Remove barriers and/or stigma around this engagement.
		Create spaces where employees can focus without distraction.	Create or obtain space/tools etc. for engaging with intense interests.
Ready to reconnect with others	Seek out or create intense interest groups and/or neurodiverse community.	Understand the need for neurodiverse community, and for community based around intense interests.	Understand the need for neurodiverse community, and for community based around intense interests.
	Understand that this community may not be accessible when already overwhelmed.	Understand that this community may not be accessible when already overwhelmed.	Understand that this community may not be accessible when already overwhelmed.
		Remove barriers and create opportunities.	Remove barriers and create opportunities.
		Signpost these opportunities.	Signpost these opportunities.

Autistic adults learn for themselves how social and sensory input can be disabling, and how attempts to 'just push through' come at a cost; but this is not always clear to autistic young people, parents, carers, educators or employers. Using the qualitative themes to guide understanding and practice could benefit autistic adults whether they are able to act autonomously to support their own wellbeing, or whether their wellbeing is predominantly supported by others. Working with autistic individuals of all ages to make simple environmental changes, reduce social-communication pressures, and recognise early signs of overwhelm may reduce crisis situations. Understanding the effects of social and sensory overwhelm, and the need for 'sanctuary' and/or engagement with intense interests may be used in the first place to avoid crisis situations, or in the second place to assist a shorter, easier and less traumatic recovery. Homes, educational and care settings can provide 'sanctuary' spaces designed with autistic input, remove barriers and stigma to using these spaces, and clearly signpost them for those experiencing overwhelm. Those same settings can also remove barriers and stigma to, and encourage engagement with intense interests. Additionally, tools which reduce sensory and social overwhelm, such as noise-reducing headphones, sunglasses and stim toys should be encouraged in public spaces.

It is also important for individuals and/or those who support autistic people in services or support settings to understand the need for neurodiverse community, and community based around intense interests, but also to understand that communities are not necessarily accessible when an individual is already overwhelmed. Mantzalas's *et al.* (2022b) conceptual model of autistic burnout found that social support, a mutual exchange of resources considered to enhance wellbeing, can be both a protective and a risk factor. Shared understandings, within family, friendship and community networks can have a positive impact on wellbeing, while well-meaning but incompatible support can prolong or worsen episodes of autistic burnout.

Vignettes

Researchers should always consider the potential ethical impacts of their findings. Throughout my research I have had some concern that future decision-makers might isolate the research finding which only answers the *why* aspect of my research aim, i.e. *why do autistic adults choose to spend time alone?* While a key finding of this research project is that autistic people may need alone-time to recover from social and sensory overwhelm, this knowledge is potentially dangerous if removed from the contexts of *how* and *where* autistic people choose to spend this time. Solitude for autistic people has, in some cases, been associated with seclusion interventions in healthcare, reform and education, often leading to practices which, rather than improving mental health, has led to worsened outcomes for the individuals concerned (CQC, 2020; Titherage, 2021; Marques, 2022; Belcher, 2022).

67% of people in long-term seclusion are autistic (Care Quality Commision, 2020). It would be easy to surmise that seclusion would have positive mental health and wellbeing outcomes, given the current study's finding that autistic people use alone-time to recover from social and sensory overwhelm. However, the Care Quality Commission's (CQC) 'brief guide to seclusion rooms' (2019) recommends that the design of seclusion rooms should include limited furnishings, externally controlled lighting and externally controlled heating. In contrast, my survey results found that having control over the sensory environment is felt to be the most important wellbeing consideration for an indoor 'alone-time' space. Current seclusion practices might fulfil the *why* of alone-time, but they do not answer the *where* or the *how*. First-hand accounts and anecdotal evidence suggest that theory does not yet lead to common praxis in the field of autistic wellbeing. The following vignettes, from the previously published stories of Beth, Hannah and Alexis, give some context to how a lack of understanding around overwhelm and how autistic people self-regulate through alone-time, can cause trauma which could have otherwise been avoided; and how autistic-informed policy and practice recommendations, such as those detailed earlier in this chapter, might result in preferred mental health and wellbeing outcomes for autistic people. Please note that real names have been used here; Beth's story has been extensively publicised by her father, with consent from Beth, and Hannah and Alexis have both published their experiences under their own names.

Vignette 1: Beth

Aged 15, Beth's admittance to a noisy and overwhelming ward in a secure hospital triggered fight or flight reactions which were 'managed' by restraint in an empty seclusion room with no bed, chair, duvet or access to the iPad she had previously used to calm herself down (Changing Our Lives, 2022). As her behaviour became more 'challenging' (including aggression and self-harm) the hospital's response was to sedate her and not allow her to access clothes or contact with other people beyond through a small hatch in the door. It took three years of campaigning before her parents were able to get her care transferred to a specialist setting which understood her environmental needs. Staff now support her in making decisions over the décor of her room, owning pets and spending a great deal of time outdoors, and her parents report that these decisions help her to feel happy and calm.

If her previous nursing staff had understood Beth's needs in terms of the current study, i.e. (1) Beth's experiences with social and sensory overwhelm, (2) her needs for 'sanctuary' and (3) her needs for engaging with her intense interests (namely, guinea pig videos), it seems likely that three years of highly traumatic experiences could have been avoided.

Vignette 2: Hannah

Autistic autism researcher Hannah, in her account of experiencing mental health crisis care in the assessment ward that she voluntarily admitted herself to, described a ten-day stay with a bedroom with no outdoor window, control over the thermostat, or access to her confiscated phone charger or sketchbook and pencils (Belcher, 2022). She was not held in isolation and she was surprised to find the camaraderie and support of the other patients helpful. However, the sensory environment was overwhelming: factors such as noise, heat, lack of fresh air, and unappetising food resulted in increased anxiety and meltdowns, and she was unable to self-regulate without the personal items she was not allowed access to.

As for Beth, it would seem likely that Hannah's experiences would have been more positive had she (1) had more control over the sensory aspects of her stay, and (2) had access to the regulatory tools she had brought with her.

Vignette 3: Alex

Alex was placed in seclusion multiple times after sensory overwhelm induced meltdowns while she was in hospital (Quinn, 2018). At one point she was secluded for eight days with only a mattress in the room. After three and a half years of being detained under the Mental Health Act, during which time she was variously drugged and restrained, she escaped and has not returned since. Her account provides a good example of why therapeutic spaces in particular need to be designed with input from service users:

> *"I entered hospital for an initial 72 hours' intervention. Due to a catastrophic clash between my autism and the environment, I became overloaded and entered a*

> *damaging cycle… My different and sensitive autistic neurology was at the mercy of those who held the keys. I began to look as they described – violent and dangerous because I couldn't control myself."* (Quinn, 2018, p.4).

The sensory environment described by Alex contrasts strongly with the environments that the current study's qualitative participants and quantitative respondents described as being beneficial for their wellbeing; in particular, the ability to control aspects of sensory input within a room in which the occupant is alone. It is imperative that the design of mental health wards include autistic user-input if it they are to have positive mental health and wellbeing outcomes.

So far, this chapter has discussed research outputs in terms of recommendations for future policy, practice and research. I plan to disseminate these outputs on completion of this thesis through usual academic channels such as publication and conference presentation, and also through channels more easily accessible to the autistic and wider autism communities such as through social media and workshops. The final section of this chapter discusses various aspects of ethical dissemination

7.2 Dissemination

Rather than allowing my research findings to gradually trickle-down from academia to practice, I aim for my research to not only impact academic understandings of autistic wellbeing and inform institutional decision-makers, but also to directly reach autistic people and their allies, including those who do not or cannot access the academic literature. In the following paragraphs I briefly discuss the importance of ethically disseminating research findings, particularly given that sharing autism research respectfully and accessibly is not as widely practiced as it should be.

Autism research necessarily requires reading and processing literature that is demoralising and degrading about the autistic community (Botha, 2021b; Bertilsdotter Rosqvist *et al.*, 2023). As discussed in Chapter Two, aetiologic understandings of autism have evolved greatly over the past decades, and with it the language used to describe autism (Monk *et al.*, 2022). Despite six decades of a medical framing of autism, rife with dehumanising language, such as Løvaas's belief that, "*You have a person in the physical sense - they have hair, a nose and a mouth - but they are not people in the psychological sense*" (Chance, 1974),

Autism research has only begun to reflect a gradual shift towards emancipatory framings in the past two decades. Much of this shift is owed to advocates in the Autism Rights and Neurodiversity movements, as described in Chapter Two. However, this shift is not fully embraced by the wider field of autism research; the rejection of disease-deficit-and-disorder language is still seen as a threat by some scientific communities. Recently, Singer *et al*., (2022) called for the freedom to use a full 'semantic toolbox' including terms such as *deficit*, *risk*, *co-morbidities*, *symptoms*, and *prevention*:

> *"No one should have the power to censor language to exclude the observable realities of autism. Scientists and clinicians must be able to use any scientifically accurate terms necessary to describe the wide range of autistic people they study and support, without fear of censure or retribution."* (p.497)

This argument is frequently used in defence of deficit-based language, with the reasoning that it is not used to describe autistic people who might be considered high-functioning (verbal, educated, able to live autonomously etc.), but those considered to be 'severely' or 'profoundly' autistic (non-verbal, low-IQ, unable to live independently etc.). This argument dismisses several important features: (1) using deficit-based language is disrespectful to the autistic community as a whole through making subjective value-judgements (Dwyer *et al.,* 2022), (2) deficit-based language should be avoided whether or not the research will be read or understood by autistic people who are additionally disabled (Collis, 2023), and (3) the terminology that Singer *et al*., defends lacks specificity and is therefore less scientifically relevant than the medically framed, clinical terms they defend (Natri *et al*., 2023; Bottema-Beutel *et al*., 2020).

A further issue surrounding the language used to disseminate autism research revolves around incomplete understandings of neurodiversity and critical autism theories, an issue that has been dubbed neurodiversity-lite (Neumeier, 2018). Such research may reference literature and theories developed within more critical understandings, while still working within a framework of autism-as-deficit. For instance, a recent publication on transforming autistic wellbeing refers to many of the emancipatory studies I have discussed in this thesis and, in line with the social theory of disability, acknowledges external detrimental impacts to wellbeing (including lack of autonomy), before describing how autistic people failing to develop ‘Dynamic Intelligence’ prevents them from overcoming disabling obstacles (Gutstein & Sheely, 2023); thus misunderstanding the social theory it purports to align with. Meanwhile Baron-Cohen, who arguably developed some of the most problematic autism theories (see Chapter Two) and is currently the principle investigator for a large-scale study investigating genetic and environmental aspects contributing to autism, has in recent years spoken of the usefulness of the neurodiversity paradigm; while describing which autistic people may benefit from a neurodiversity framing, and which may not, before clarifying,

> “*… there is a case for all of the terms “disorder,” “disability,” “difference” and “disease” being applicable to different forms of autism or to the co-occurring conditions.*” (Baron-Cohen, 2019).

Autism researchers who are committed to a pathologised view of autism can derail neurodiversity-led research by pitting ‘difference’ against ‘disability’. In contrast, neurodiversity-led autism research recognises that difference and disability can and do co-exist in respectful, ethical autism discourses. As discussed in Chapter One, blaming autism itself, or an assumed severity of autism, for the collectively low wellbeing of the autistic population does not encourage effective research into strategies which may improve autistic wellbeing. Autism mental health and wellbeing research which denies or only pays lip-service to neurodiversity or critical autism theories can cause damage to the autistic community through paternalistic assumptions about what autistic people want or need for their improved wellbeing, rather than listening to community priorities. This practice is somewhat in line with colonial attitudes.

Scholars seeking to decolonise research ask ‘who owns the knowledge?’ (South West Doctoral Training Partnership roundtable, 2021). This question specifically refers to research with indigenous communities, from whom knowledge and stories are commonly repackaged and claimed by academic communities without consideration to context or ownership. However, there are some parallels with autism research. Autism research has not only traditionally been carried out *on* rather than *with* autistic communities, but the generated knowledge is often inaccessible to these same communities, whether hidden behind paywalls or written using academic jargon. Effectively and accessibly communicating research findings with participants is an important feature of accountability; an acknowledgement of the effort involved in taking part (Aidley & Fearon, 2021). When research participants from the autistic community volunteer time and energy to offer their stories of what it means to be autistic, sharing the resulting research findings with the autistic community freely and accessibly is an ethical imperative. The resulting community ownership of the research findings is also key to emancipatory autism studies of which dissemination is required to be widely, freely and accessibly available (Bertilsdotter Rosqvist *et al*, 2019; Chown *et al*., 2017).

Soon after I had written up my qualitative findings I wrote a blog post describing my research and providing a plain language summary of the four themes on AutismHWB.com[14], ensuring that I had covered accessibility features such as reducing or explaining technical terminology, writing short paragraphs, using a clear visual theme, providing image descriptions and using fonts that could be read with screen-reader technology. Hundreds of autistic people, activists, advocates and academics shared the blog post on social media with the result that over 3,000 people read it within the first week of publishing. Through tweets and direct messages, readers let me know that they appreciated the content and the accessibility of the post, with many noting (1) consistency with their own experiences, (2) the potential impact to educational settings, (3) hopes for the continuation of research in this field, and (4) that the post was easy to read and held their attention. To date, this post has been read nearly 7,000 times. Shortly before completing this thesis I also wrote a blog post describing my quantitative findings. Although I adhered to the same accessibility features, this post had less impact, which likely reflects my recently lower ‘reach’ on Twitter since Musk’s changes to the platform (as described in Chapter Five).

Chapter conclusions

This chapter has discussed (1) the CAG recommendations arising from my PhD work, (2) my own suggestions for how my qualitative themes might be used to support autistic wellbeing in various contexts, and (3) ethical dissemination of the research findings. Understanding how alone-time may benefit autistic people in a range of contexts has the potential to improve autistic wellbeing at both individual and collective levels, but it is important that

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[14] AutismHWB.com is the community autistic health and wellbeing site that I founded on completion of my MRes, and now run with a small team of other autistic people.

alone-time is not viewed in terms of a ‘quick-fix’ or ‘tick-box exercise’. As has been discussed in earlier chapters, autistic wellbeing and strategies to improve autistic wellbeing must be considered through theoretical lenses which account for autistic people’s marginalisation in society. Autistic people should be able to access alone-time, without feeling that this time is stigmatised or pathologised; similarly, they should be able to access knowledge about alone-time and its benefits, without being exposed to stigmatising or pathologising stances or language. The next chapter concludes my thesis by summarising the contributions my research makes to knowledge in the field of autistic wellbeing, and offering my reflections on my research methodology and findings.

Chapter Eight: Discussion

> "A truly radical approach would be research that aims to understand autistic people, instead of the entity we call autism"
>
> - *Pearson et al. (2021, p.2243).*

I began my PhD in the midst of the Covid-19 lockdowns, writing up my project registration at the kitchen table - when it wasn't being used for family meals, family board games and seemingly endless online meetings. With a lack of in-person social interactions outside of our household, we kept up our collective morale by connecting with each other frequently throughout each day. In many ways it was glorious. In many ways it was incredibly difficult. During the past three years, the amount of time I have had to myself has gradually increased, and with it my ability to think, focus and write. With regular access to time and space alone I have thoroughly enjoyed what I now recognise as daily cycles of retreating, regulating and reconnecting. As an additional bonus, I finished the final draft of this thesis in solitude; my family gave me the gift of an uninterrupted five days of alone-time at home to immerse myself in reflecting, writing and refining. Rather than rushing my final words, I have been able to sit with them and enjoy them; to look back at what I have learned over the past three years, and to feel grateful that I've had the opportunity to share what I have learned with others.

My PhD research used an exploratory sequential mixed-methods design with a pragmatic framing to explore self-managed time and space alone as a wellbeing strategy for autistic people. While I recognised this strategy as vital for myself, I wanted to know if other autistic people also placed value on alone-time for their wellbeing and, if so, how and where they spent this time. Having presented and discussed the literature, methodology, and findings for my research in earlier chapters, this final chapter provides a more reflexive synopsis of these elements. Thus, this chapter concludes my thesis with (1) a summary of answers to the research questions, (2) a discussion of the contribution my research will make to the literature, (3) methodological reflections (including strengths and limitations) and finally, (4) my personal reflections on alone-time and autistic wellbeing.

8.1 Summary of findings and contribution to knowledge

My research aim was to explore the wellbeing benefits of time alone for autistic adults. My research questions were:

RQ1: To what extent do autistic adults choose to create regular time alone?

RQ2: How and where do they choose to spend this time?

RQ3: Is there an association between using this time and space, and self-reported levels of wellbeing?

As detailed in Chapters Four and Six, the two studies (one qualitative and one quantitative) included in this study provided the following contributions to knowledge (these are discussed further in the next section):

- Alone-time benefits autistic adults in recovering from social and sensory overwhelm, self-regulating, recharging social energy, and improving or maintaining wellbeing.
- Autistic adults may desire social interaction but find it difficult to access when experiencing overwhelm (or the aftereffects of overwhelm) from social environments.
- Some autistic adults feel that they only experience alone-time when they are completely alone; others may still benefit from alone-time when they are not completely alone, as long as they feel free of expectations to interact with others.
- Autistic adults choose a wide range of activities for the purposes above and tend to prefer either indoor spaces where they have control over the sensory environment, or outdoor spaces where they are unlikely to need to interact with others.
- There is little statistical evidence that the average number of daily alone-time hours *had* or *wanted*, has an association with self-reported wellbeing. Also, there is little statistical evidence that the *difference* between the average number of daily alone-time had and wanted, has an association with self-reported wellbeing. Positive effects of alone-time (such as mitigating the effects of overwhelm, and increasing feelings of energy, joy and the desire to reconnect with other people) may have more impact on immediate psychological measures than with estimates of wellbeing over two weeks.

The exploratory sequential mixed-methods design provided an opportunity to increase the cultural and contextual sensitivity of the quantitative study through embedding personal and cultural autistic experiences into the survey questions. Additionally, guidance from the CAG helped to help ensure that the study design, procedures and output was more accessible for participants, respectful of wider community views and relevant to community needs.

8.2 Contribution to literature

Although Neurodiversity as a concept began to take shape in the 1990s (Dekker, 2020; Tisoncik, 2020; Kras, 2009) neurodiversity informed research about autistic wellbeing (i.e. understanding that autistic people's wellbeing can and should be improved through changing the social environment, rather than the autistic person) is still underrepresented in the autism literature. Considering that the majority of autism research has been carried out within a historically dominant pathology paradigm which classifies autism as a disorder, and situates autistic disability within the autistic person (Walker, 2021), it is perhaps not surprising that the literature has only recently begun to reflect the effects of social environments and social expectations on autistic wellbeing (Manning *et al.*, 2023). My PhD mixed-methods research has novel findings because, although alone-time as a self-directed wellbeing strategy is often discussed within the autistic community, there is a clear gap in the research exploring this phenomenon in the literature.

Despite the gradual increase in research describing how environmental aspects - such as sensory and social input and expectations - impact the mental health of autistic people, targeted outcomes for mental health and wellbeing interventions still commonly aim to reduce autistic presentation in terms of communication and behaviour (Featherstone *et al.*, 2022), and risks of harm from mental health interventions for autistic people are under-reported (Linden *et al.*, 2022; Bottema-Beutel *et al.*, 2021). In Chapter Two I critiqued the use of Applied Behavioural Analysis for its intent to improve quality of life through eliminating 'autistic behaviours', but did not engage with further deficit-led literature describing currently used anxiety and depression interventions for autistic adults such as ketamine therapy (e.g. Wink *et al.*, 2021; Kastner *et al.*, 2015) and electroconvulsive therapy (e.g. Smith *et al.*, 2022). Such studies, which carry high risks of harm, reflect a medical model of autism and do not consider disability arising from social structures. Meanwhile, autism mental health and wellbeing research which highlights environmental considerations or self-managed strategies, still remains largely untested in intervention or other empirical studies.

My findings support knowledge that has previously been developed within emancipatory autism research. In Chapters Two and Three I introduced four theoretical concepts which have been influential in emancipatory autism research: the Social Model of Disability, the Neurodiversity Paradigm, Monotropism, and the Double Empathy Problem (Oliver 1998; Walker 2021; Murray et al., 20015; Milton, 2012). Together, these theories situate much (but not all) autistic disability and poor mental health within a mismatch between autistic needs and social environments which are not inclusive of these needs. Emancipatory autism theories reframe the assumed autistic traits described in DSM-5 as "*persistent deficits in social communication and social interaction*" and "*restricted, repetitive patterns of behaviour, interests or activities*" (American Psychiatric Association, 2013), as breakdowns between autistic and non-autistic needs, experiences and communications; as regulatory practices; and as activities which support wellbeing through bringing joy. I now discuss the significance of my own research to autism research studies within this emancipatory research field.

A key finding from my research was that alone-time may mitigate the distressing overwhelm that autistic adults may experience from certain social and sensory environments. As discussed in Chapter Four, there has been a growing interest in the negative effects arising from social experiences and sensory experiences (e.g. Millington & Simmons, 2023; Verhulst, 2022; MacLennan *et al*., 2022a; Belek, 2019). Autistic adults may be more impacted by social environments than adults who are not autistic, given innate differences in social and sensory processing, and likelihood of monotropic processing (Strömberg *et al*., 2022; Garau *et al*., 2023; Murray *et al*., 2005). The Double Empathy Problem (Milton, 2012) was apparent in the accounts of my interview participants who spoke of the disconnect between how they and their colleagues experienced social and sensory input in the workplace and how this disconnect invariably left their needs for accommodations to support focus and improve wellbeing unmet.

Sensory considerations in the design of the built environment, such as lighting, sound, air quality, and temperature, impact the degree to which autistic people are included and are able to participate (Black *et al.*, 2022); and adapting sensory features of shared spaces can reduce feelings of overwhelm and increase wellbeing (Martin *et al*. 2019; Brand & Gaudion, 2012). While clear and detailed guidelines exist to inform such considerations (such as Mostafa, 2015; British Standards Institution, 2022; NDTi, 2020a & 2020b), the disabling effects of not carrying out these adaptions in public spaces does not yet appear to be part of the public consciousness beyond campaigns such as the National Autistic Society's Autism Hour (during which participating businesses dim lights, reduce the volume of background music, train staff about autism, and increase public awareness (National Autistic Society, 2017). My findings indicate a clear need for further research into the impact that social and sensory environments have on autistic people, and further research into how to reduce factors that cause overwhelm and increase factors that improve autistic wellbeing.

A second key finding was that a need for alone-time sometimes indicates a response to overwhelming social and sensory input and/or need to socially mask. This finding is supported by research indicating that autistic people's negative experiences of social input, sensory input and social masking contribute towards anxiety and depression (Black *et al.*, 2023; Verhulst *et al.*, 2022: Millington & Simmons, 2023; Hull *et al.*, 2021). Dedicated alone-time, during which autistic people can retreat from the outside world, regulate emotions and recharge energy, has previously been suggested as helping to avoid and/or recover from autistic burnout, a debilitating state of chronic exhaustion characterised by loss of functioning and reduced tolerance to social and sensory stimuli (Raymaker et al., 2020; Higgins *et al.*, 2021; Mantzalas *et al.*, 2021). As my findings indicated that alone-time benefits short-term or day-to-day impacts on wellbeing, alone-time should thus be explored further in moderating both chronic *and* acute states of poor health and wellbeing.

It would appear that one key benefit of alone-time, whether that time is spent in complete isolation, or just without any requirement to interact with others, is that of reducing mental health challenges for autistic people through avoidance of, recovery from, and protection against social and sensory overwhelm. As such, access to safe or sanctuary spaces where people can retreat from distressing social and sensory input (and the need to socially mask) should be prioritised, particularly within public spaces (Doherty *et al.*, 2023; MacLennan *et al.*, 2022a & 2022b), but also within any other spaces where autistic people might feel overwhelmed from social interaction and sensory input (Black *et al.*, 2022; British Standards

Institution, 2022; Mostafa, 2015). My qualitative findings indicated that lack of access to easy, non-stigmatised and sensory-appropriate retreat or sanctuary spaces had negative impacts on wellbeing, particularly in terms of distress, physical and emotional pain, confusion, exhaustion, difficulties communicating, and difficulties with executive functioning (such as planning ahead, working memory and focussing); all of which are commonly associated with autism.

A third key finding concerns the range of spaces where autistic adults chose to spend their alone-time; particularly indoor spaces where the sensory aspects can be moderated to suit the individual (as discussed above), and which feel safe and cosy, to remote outdoor spaces where there are few or no other people around. As detailed in Chapter Seven, recent literature has reflected a growing interest in (1) how the sensory aspects of social spaces impact autistic inclusion and autistic mental health and wellbeing, and (2) the design of designated quiet spaces. However, there has been very little research into how remote and natural spaces impact autistic wellbeing, although Friedman *et al*. (2023) highlighted the link between nature and wellbeing for autistic adults during the Covid-19 lockdowns, and MacLennan *et al*. (2022a & 2022b) found that autistic adults often seek out natural spaces and find them enabling. My findings indicate that some autistic adults find accessing such spaces vital for their wellbeing, whether for regular periods of recreation or during longer periods of restorative immersion in the natural world. In particular, preferred outdoor spaces were natural, rural/coastal, and with few or no people around. My qualitative findings drew attention to how autistic people felt less inhibited and more connected to the world around them in these spaces. The wellbeing benefits of recreation and/or immersion in the natural world for autistic people would be worth exploring in future research.

My research indicates that time alone in preferred spaces (including natural spaces) while engaging with preferred activities may have considerable wellbeing benefits for autistic people. This is supported by previous research contributing to understandings of autistic wellbeing such as that by Wood, 2021; Lam *et al*., 2020; Grove *et al*., 2018; Hickey *et al*., 2018; and Milton and Sims 2016. The relationship between solitary spaces and activities with wellbeing benefits for autistic people may not be particularly surprising but it is little explored in the literature. Engaging in solitary activities over social activities appears to be preferred by autistic people and confers increased wellbeing; conversely, people who are not autistic tend to prefer social activities over solitary activities (Stacey *et al*., 2019; Smith *et al*., 2019; Bishop-Fitzpatrick *et al*., 2017). When these findings are viewed through an autism-as-deficit lens there is a risk of pathologising autistic people's preferences and needs for time alone and concluding that autistic people should be taught social skills in order to benefit from increased social interaction (e.g. Parenteau *et al*., 2023). However, an emancipatory framing of the need for alone-time, such as used in the current study, may contribute to reduced stigma, better support, and validation for autistic people who recognise their need for emotional and physical regulation through alone-time.

Finally, a need to engage in preferred types of social connection was not an intended focus for my research. Nonetheless, one of my ethical considerations (see Chapter Three) was treating the participants as experts on their own experiences and understandings (Karnieli-Miller *et al*., 2009). As such it was important to reflect that my participants chose to talk about their need for social connection, and their preferred ways to connect socially. A need for social connection appears to be intrinsically linked with a co-existing need for solitude, and is discussed in research focussed on autistic burnout and loneliness for autistic people (such as Mantzalas *et al*., 2022a; Quadt *et al*., 2021). One benefit of alone-time appears to be that of increasing the energy and desire to socially connect; without access to alone-time, socialising becomes less desirable and more difficult to engage in. Further, if socialising is associated with social and sensory overwhelm experiences for autistic people, then increased loneliness and social isolation may result. As loneliness and feeling socially isolated significantly reduce wellbeing for autistic people (Quadt *et al*., 2021; Pellicano *et al*., 2022; Mosely *et al*., 2021; Elmose, 2020), it would seem likely that future research which explores how and where autistic people prefer to socialise would gain findings of high relevance to the current study. If autistic people's social experiences are less overwhelming, then (1) autistic people may feel less lonely and isolated, and (2) autistic people's alone-time may be used more for enjoyment than for recovery. Both outcomes would thus appear to support improved autistic wellbeing.

In Chapter One I discussed how autistic wellbeing has been neglected in the literature due to misunderstandings around (1) whether autistic people can actually experience wellbeing, (2) the epistemic validity of autistic people's individual and collective knowledge, and (3) whether autistic people's wellbeing goals should reflect those of the wider population or whether they might reflect different priorities. I believe that my PhD research contributes findings which may help correct such misunderstandings. My analyses of the data collected from autistic people suggest that autonomy and agency (the freedom to choose and the resources and ability to act on choice) over alone-time to (1) recover from negative impacts of the social environment, and/or (2) immerse oneself in preferred interests and sensory experiences, contribute to improving and protecting autistic wellbeing. Alone-time can positively impact autistic wellbeing when autistic people have the autonomy and agency to decide when, how and where this time is spent. While there are many similarities between why, how and where autistic people might want or need alone-time, the choice of environments and activities may be contextual and reflect whether alone-time is needed for retreat and recovery, for recharging energetic resources, or even for pure enjoyment.

8.3 Methodological reflections

I reflect here on specific methodological elements of my PhD research as a whole - pragmatic framing, positionality, working with the CAG, representativeness and intersectionality - and how the implicit strengths and limitations within these elements have developed my personal understandings within the research area. Combined, these elements reflect my commitment to ethical research through treating participants and respondents - members of the autistic community - as experts on their own experiences; and aiming to reflect their experiences and needs with respect. Following these reflections, I summarise additional explicit strengths and limitations in my research.

Pragmatic framing

In Chapter Three I justified a pragmatic framing of my research, an acknowledgement that the contribution to knowledge might be considered in terms of contributing to ‘real-world’ practice resulting from epistemological practicality, methodological considerations based on ‘what works best’ (Creswell & Plano Clark, 2018). Recently I had the chance to reflect on how a pragmatic framing is ideally suited to empirical autism research, in that it allows for both singular and multiple realities, and both biased and unbiased perspectives (Creswell & Plano Clark, 2018). During the final six months of writing this thesis I attended a two-day international neurodiversity conference, “It Takes All Kinds of Minds 23”. The conference bought together a wide range of academics, activists and advocates from a number of disciplines, including psychology, sociology, philosophy, neuroscience, health and education, to discuss research relevant to individual neurodivergencies as well as the neurodiversity paradigm itself. Over the two days I noticed an apparent division in how the various disciplines conceptually framed neurodiversity and individual neurodivergencies.

As discussed in Chapter Two, aetiologic understandings of autism have shifted several times over the last 80 years but autism as a concept is still not universally agreed upon (Chapman, 2020a; Ryan & Milton, 2023). As such, any dominant explanation of autism, of which the most current posits that autism is a heritable neurological difference, is what Bhaskar *et al*. might term a 'fictitious placeholder' (2018). But even at ITAKOM 23, with a focus on neurodiversity, some presenters stated their commitment to either one of two apparently opposing viewpoints around neurodivergent identity. The first was that neurodiverse 'categories' such as Autism, ADHD, and being neurotypical were distinctive, tangible, and likely biological in nature. The second was that these categories should not be considered fully defined, and that they may represent fluid states of being, with a high degree of overlap.

I noticed that this division in viewpoints appeared to reflect researchers' disciplinary backgrounds; carrying out empirical research requires distinctive categories, particularly in case-selection or sampling practices, while conceptual research is less constrained in this way. Given that autism and neurodiversity are both concepts developed and framed within the languages, literatures and philosophies of the global North, and thus not globally accepted, these apparently opposing views, do not necessarily need to be exclusive of each other; their appropriateness may be contextual. A commonly agreed concept of autism is generally useful and necessary, but no concept should be considered to define an individual or to determine the type or level of support needed at any given time by that individual. Knowing that autistic people are likely to need alone-time to reduce social and sensory overwhelm and/or improve wellbeing does not dictate that all autistic people will want to access and use alone-time, or indeed find it useful at any or all life stages. If we do not know for certain what autism is, how can we know for certain what autistic people need?

Rather than attempting to strengthen objective assumptions of what autistic people need for wellbeing, or seeking to describe an infinite breadth of autistic wellbeing experiences, using a pragmatic framing to answer my research aim meant that I sought to produce 'best possible' findings which could impact practical applications, while acknowledging that understandings are still incomplete (Creswell & Plano Clark, 2018; Wheeldon & Åhlberg, 2012). The CAG recommendations for policy and practice (Chapter Seven) reflect what we currently know about autistic adults' wellbeing needs, given published research and community 'knowing', and what we currently understand alone-time to be (given the current study's findings and the wider literature available). However, the CAG recommendations for future research, acknowledge that there is more to be learned; results from future studies may suggest more appropriate and useful policy and practice suggestions.

It is not possible to tell what my research findings would have been had I chosen a philosophical framework which dictated a reliance on more deductive or more subjective reasoning but, as discussed in Chapter Six, a more theoretically driven research design would likely have missed out on at least some of the rich qualitative findings that shaped the quantitative survey. Alternatively, it may have been more difficult to make logical conclusions and suggest practical applications from a more data-driven and/or constructivist piece of research with similar aims. As it was, I believe that the pragmatically-framed, exploratory sequential mixed-methods research design was effective in delivering practical and transferable findings for the autistic community, based on current, neurodiversity-informed understandings of autism and autistic wellbeing potential.

Positionality

Taking an intersubjective viewpoint means I recognise in my research that my 'knowing' is based on my positionality, but is also socially mediated in that this 'knowing' is shared to varying degrees with others that I interact with (Given, 2008). The most obvious aspect of my positionality, my relationship to the research subject and the community that I am researching, is that of an insider researcher, an autistic person studying the needs and experiences of other autistic people. I also considered and even blogged about my need for alone-time for several years before undertaking this research. But positionality is not limited to demographic characteristics or relationship to the research theme; in my case, an autistic white cis-woman raised in the UK who considers her wellbeing to be impacted by the quantity and quality of her alone-time. Positionality also refers to an active reflexivity, a continual assessment of how our positionality interacts with those who take part in our research and those who read it; and what assumptions we make about our own findings and conclusions in relation to our positionality (Soedirgo & Glas, 2020; Finlay, 2002).

Part of this reflexivity was enhanced by taking an intersubjective viewpoint, which meant that not only did I need to consider my own engagement with the subject matter, but that I needed to consider what the CAG, my supervisors, and the pilot participants ‘brought to the table’ in terms of their own engagement with the subject matter (Finlay, 2002). Changes in methodology (replacing researcher-directed diaries with preparation sheets), survey questions (asking participants to qualify the degree to which they needed to be alone) and even the overall research aim (from anxiety to wellbeing) were influenced by interaction with other ‘players’ in the research who had different positionalities and stances from myself. The CAG members were all autistic women and will have had many similar experiences to myself; but intersecting additional neurodivergencies, disabilities, life experiences and research interests meant that we had different ways of approaching the research materials and had different foci when creating the recommendations. I believe that both our similarities *and* our differences enhanced the research. Decision making through collaboration with the CAG relied on abductive reasoning from all of us: we used our combined intuition and expertise to make logical inferences from the data, and adapted the research methods accordingly. When I registered my PhD research project in early 2021 I had some pre-formed ideas about why alone-time might be beneficial (as discussed in Chapter One), but discussions with the CAG during the research highlighted that the findings prompted different responses and further questions from each of us. Reflexively challenging my own assumptions while also working collaboratively meant that the research itself could evolve and develop beyond my early proposals outlining study design, data collection and analysis.

There could be a post-positivist argument against a lack of objectivity and mitigation of bias where the researcher’s reflexive approach includes acting on intersubjective reflections throughout the research. But I am not convinced that autism research to date which has claimed objectivity has been of particular benefit to autistic people. Looking objectively at ‘autism’ appears, historically, to have reflected researcher bias in ‘othering’ autistic people, resulting in increased stigma and lack of access to appropriate support and services.

Conversely, the emancipatory field of Critical Autism Studies argues for epistemological validity through autistic research leadership (Ryan & Milton, 2023), and sees subjectivity as a benefit to autism research. In Chapter One I suggested that autism is often understood in terms of 'how the world experiences autistic people' rather than 'how autistic people experience the world'. I believe that a commitment to intersubjectivity, both from personal reflexivity and from collaboration with the CAG was valuable in gaining further understandings of how autistic people experience the world, and in gaining practical solutions for improving that experience.

As discussed during the introduction and both methodology chapters, undertaking the research described in this thesis was influenced by years of lived experience and community knowledge; the implicit and explicit biases that arise from this type of insider research have been justified throughout the thesis. However, the research methods, findings, reflexivity and writing up for this PhD were also likely influenced by my own autistic ways-of-being. For instance, as described in Chapter Three, I did not offer phone-interviews as I am unable to process communication over the phone, and I did not keep a reflexive diary as this did not help me to process or reflect on the interview data. Additionally, this thesis reflects some aspects of how I read and process written information, although I was not always aware of how these might differ from other candidates writing until they were pointed out, e.g. (1) each chapter began with a citation-free introduction because I prefer chapter introductions that summarise what is to come without providing details that I might find overwhelming, (2) the fonts and formatting styles were used to make the thesis 'open' and easy to read, which I find useful as I have challenges with visual tracking, and (3) the thesis was not written in order, rather it was used as a working document which included reflexive writing, method 'instructions' and observations. This final point supported my personal challenges with working memory.

Working with the community advisory group

It has been apparent to me while undertaking this PhD that, even as an autistic person with easy access to community knowledge, it is easy to make incorrect assumptions or generalisations based on prior knowledge and/or my own experience. As discussed in earlier chapters, including the CAG as part of the study design was valuable in that they often saw what I didn't, and questioned me when I hadn't considered alternatives. Having additional community input from people with different personal and professional positionalities was valuable in terms of improving study design, procedures and output. In particular, the group members foresaw that researcher-directed diaries would place a higher burden on participants than an online preparatory sheet, and they confirmed that using a wellbeing scale would be more meaningful, relevant and sensitive to the autistic community's experiences than using an anxiety scale.

Firstly, as described in Chapters Three and Five, the group's input increased the accessibility of the materials (participant information, consent, interview preparation and survey items). Materials are not always fit for purpose in terms of accessibility, which affects the validity of research (Aidley & Fearon, 2021; Fletcher-Watson *et al*., 2021; Nicolaidis *et al*., 2019). The group members had varied personal and professional experiences of both using and creating research materials which meant that their feedback helped me ensure a far wider level of accessibility for the participants and respondents than if I had worked only from previously available accessibility guidelines, such as those discussed in Chapter Three.

Secondly, as described in Chapter Five, when I described to the CAG how the qualitative findings did not suggest a relationship between alone-time and anxiety, but rather alone-time and wellbeing, they were quick to recommend a change in the research aim (a decision which I had previously considered but not committed to); and the adoption of the Warwick Edinburgh Mental Well Being Scale, which, when I later compared it with other wellbeing scales, looked to be the most suitable measure. Finally, the list of recommendations presented and discussed in Chapter Seven resulted from a collaboration with the group and thus reflected four people's engagement with the research findings rather than just my own; while the CAG recommendations focussed on just a few of the research findings, the scope and range of these recommendations were wider than if I had only considered them by myself.

It should also be recognised that working with an advisory group increased the burden of time and personal energy for the research. This was a learning process for me in terms of:

1. setting up synchronous meetings and collaborating asynchronously on materials with people with varied home and work backgrounds and commitment to the research

2. managing my own personal discomfort around the two team members who left during the research (one for reasons outside of the study, and one who stopped engaging without giving a reason).

These both likely relate to communication, which has previously been documented as a particular difficulty in participatory autism research (Pickard *et al*., 2021). The combination of sharing expectations of input, managing team deadlines and accommodating members' requirements needed careful consideration, and was something I found challenging. A potential contribution towards group members dropping out may have been due to the length of the study; if I have the opportunity to work with an advisory group over a long time-period again, I will consider setting a clear limit on the amount of time that members might commit to; after this time, they might re-commit to another phase if wished, but I would otherwise assume to form a new group. Writing a clear summary at the end of each phase would, as it did in the current study, enable new group members to catch up with any previous work. These considerations may also be pertinent to participatory research in general, particularly when working on a study or collection of studies over a long time-period.

Representativeness and intersectionality

In Chapter Two I discussed how the historical bias in predominantly identifying or diagnosing white boys and men with a previously agreed-on presentation of autism has led to bias in autism research; and, in turn, how bias in autism research has led to research findings which do not reflect the needs and experiences of the autistic population. Reflecting on the resulting lack of representativeness in existing research is necessary to lessen this limitation in future research. While being autistic is a core part of an autistic person's identity, people's identities are multifaceted, comprised of fluid and interacting aspects (Bertilsdotter Rosqvist *et al*., 2022). Additionally, many autistic groups including older autistic people and those identifying as LGBTQIA+ are underrepresented in research (Waldock & Keates, 2023). It is necessary to consider representativeness when interpreting my findings rather than make assumptions on the relevance of the findings to the entire UK adult population. Basic demographic data was used to describe the qualitative participants and quantitative samples, but (as described in Chapter Five) it was not a research aim to identify similarities or differences between the needs and experiences of, for instance, autistic participants of different genders, ethnicities, disabilities or economic backgrounds. As discussed in Chapter Seven, further research could explore differences to generate more detailed understandings and shape more targeted recommendations for policy and practice.

It is difficult to state with any certainty how representativeness in research with the autistic population might compare with that with the general population, due to historical sampling biases in autism research and diagnoses. However, given that I recruited via social media, some discussion of the likely representativeness in online surveys undertaken by autistic adults is necessary (I was not able to find research on representativeness in recruitment for other types of studies). Autistic adults commonly use social media; even in the early days of commonly used social media platforms 80% of autistic adults used social networking sites (Mazurek *et al*., 2013). But, as with all research which recruits through social media, there are questions around sampling biases. A study (Rødgaard *et al*., 2022) on whether social media recruitment for autism studies were representative, found that of the 36 included studies, the mean male to female ratio was 1:1.6, 60% of participants were graduates, 28.7% were unemployed and 3.8% of the participants had an intellectual disability. The authors noted that these figures contrasted strongly with those from previous autism research and concluded that social media recruitment created a strong sampling bias. While these conclusions are interesting in terms of representativeness in general, they also raise questions around the sampling bias of the comparative studies discussed in that research. For instance, although the autistic male to female ratio is estimated at 3:1 (Loomes *et al*., 2017), this is likely to reflect a diagnostic bias (see Chapter Two for a critique on this bias); however, even in more general populations, surveys are commonly completed by more women than men (Sax *et al*., 2008). Meanwhile, 60% of participants having graduated, is in line with that of the UK general population at 61.1% (Gov.UK, 2021), and 3.8% of participants having an intellectual disability is close to the estimate 2.16% of learning-disabled adults in the UK (Mencap, 2020). Given these considerations, the representativeness of an autism survey, rather than being measured by comparing the demographics of the participants with those of published papers on autism, might be better compared with the wider population.

The demographic characteristics for the current qualitative and quantitative studies (presented in Chapters Three and Six) are unfortunately neither representative of the autistic UK adult population nor the UK general adult population. Rather, it seems likely that they more closely reflect (1) the immediate and wider following for my social media accounts, through whom most participants and respondents were recruited, (2) people who enjoy taking part in research, and (3) people who are invested in the results and outcomes of autism research. During the last few weeks of recruitment for the quantitative survey I included the following text in several quote-tweets (quote-tweets embed an original quote in a new tweet) which were widely shared:

> "*Still a few groups still under-represented though: 1. autistic adults who are Black, Asian and/or of mixed ethnicity, 2. autistic adults who don't have a degree, 3. autistic men, 4. autistic adults aged 60+ Please RT!*".

However, although each of these tweets were successful in encouraging more people to participate, daily scanning of the demographic results in Qualtrics showed that the proportions of these underrepresented groups did not increase. As discussed in Chapter Three, the more marginalised a group is, the more pressure they may have been under to participate in previous research, leading to 'research fatigue' creating further marginalisation in research (Huckins, 2021; Clark, 2008).

Mallipeddi and VanDaalen (2022) outline how critical disability and critical autism studies would benefit from integrating intersectional frameworks; in order to more fully understand autistic experiences, it would be necessary to gain previously underexplored perspectives of autistic people who are further marginalised by, for instance, LGBTQIA+ identities and/or skin colour. I deliberately kept demographic questions to a minimum to avoid using up too much of participants' time and so did not, for instance, ask questions regarding sexuality or gender identities. However, I was particularly interested to know whether the studies were likely to represent autistic adults from communities further marginalised by ethnicity in the UK, and was disappointed that I had failed to recruit representative samples. Rather than proactively targeting participants (as discussed in Chapter Three), for future research I would look for ways to incorporate Malone's *et al*. (2022) guidelines to help shift towards more inclusive autism research, particularly in terms of increasing participation from black autistic communities: (1) adapting research practices through establishing cultural reciprocity, (2) constructing racially and ethnically inclusive designs with participatory input, and (3) centring the voices of black autistic adults, particularly through paid opportunities for black researchers or advisors.

Alongside an increase in research with autistic adults without additional learning disabilities and/or with fewer support needs, there are calls for research which is more inclusive of those with additional learning disabilities and/or higher support needs (Long *et al*., 2023). However, there is a divide between motivations for this inclusivity. For instance, Waldock (2019) rightly calls for greater involvement from autistic adults with learning disabilities in the design of autism studies, particularly where there are challenges with normative pragmatic communication such as spoken language. On reflection, perhaps all research with people, whether autistic or not, should be held to the same standards (Aidley & Fearon, 2021). Meanwhile, other researchers claim that the increase in research with speaking autistic adults has little to no relevance for those deemed ‘severely’ autistic (e.g. autistic people who do not communicate via spoken language) and, therefore, that it detracts research funding from these same groups (Singer *et al*., 2022). Arguments against the deficit-based language used to describe multiply-disabled autistic people in this last argument aside, it is clear that autism wellbeing research could benefit from more inclusive data collection methods. Both phases of the current research were accessible for autistic people who do not communicate through spoken word, and were designed to be as accessible as possible (as described in Chapters Three and Six). However, given that the survey respondents represented a highly educated bias, it is clear that more inclusive recruitment and data collection methods are needed if future research is to reach this group.

The CAG recommended that more creative (or arts-based) methodologies might be used to collect data that more accurately reflects the heterogeneity of the autistic population in future studies about autistic wellbeing and alone-time. Studies using creative methods might be used with smaller, more homogeneous groups of autistic people, or they could be used with larger, more heterogeneous groups. Either option would be subject to differing strengths and limitations, but both could help establish a wider evidence base for the benefits of alone-time, and thus may support future interventions designed to support autistic wellbeing in home, professional and supported environments.

Additional strengths and limitations of the research

In addition to the methodological reflections discussed above, my mixed-methods research has a number of additional strengths and, as with all studies, some additional limitations.

Strengths

I believe that my PhD research demonstrates a number of strengths, including the research design, multiple development phases, and measuring positive aspects of wellbeing.

1. Research design

As discussed in Chapter Six, the exploratory sequential design (qualitative → quantitative, with an emphasis on the qualitative phase) ensured that stakeholder needs and experiences were embedded into the quantitative survey. In particular, the survey items asking how and where autistic people choose to spend their alone time were informed by qualitative findings, and so the descriptive analyses are more likely to represent autistic people's choices, rather than choices based on previous work with the general population.

2. Multiple development phases of the quantitative survey

Developing the online two-part questionnaire survey took considerably longer than I had expected, but on completion I was satisfied that including CAG involvement and carrying out both a pre-test and a pilot test were highly valuable stages in (1) improving the validity and flow of the questionnaire and (2) improving my own understanding of the research questions, and subsidiary quantitative questions. The documented changes in questionnaire design as a result of CAG involvement, pre-testing and pilot testing can be seen in Appendix O.

3. Measuring positive aspects of wellbeing

As discussed in Chapter One, positive aspects of mental health tend not to be reflected in autism research, which by and large assumes that autism is at odds with wellbeing and flourishing (Pellicano & Heyworth, 2023; Chapman & Carel, 2022). However, proponents of the neurodiversity paradigm, in challenging pathologised understandings of autistic disablement and distress, suggest that autistic wellbeing is impeded largely by societal factors (Chapman & Carel, 2022). As such, the autism 'tragedy narrative' is considered unnecessary and harmful as it suggests to autistic people, their families, autism professionals, and the wider society, that being autistic cannot co-exist with experiencing wellbeing. Interestingly, the few existing autism studies using the WEMWBS in the literature, either include additional anxiety and/or depression scales or appear to have used it to measure negative effects on wellbeing only. Although RQ3 did not show any relationship between the amount of alone-time wanted and/or had with wellbeing, using the WEMWBS rather than a measure of poor mental health acknowledged that autistic adults can and do experience wellbeing, as evidenced in some high scores at each of the time points (Chapter Six). Future research may explore the idea of autistic wellbeing even further if wellbeing measures are developed to better capture positive aspects of autistic experiences rather than normative life-goals developed within the general population (Pellicano & Heyworth, 2023).

Limitations

I identified a few limitations relating to respondent eligibility, ambiguity around *alone-time* versus *time alone*, and free-text answers.

1. Respondent eligibility

As with all questionnaires recruited and delivered online, it is difficult to assess whether all respondents are who they say they are. Pellicano *et al*., (2023) discuss a recent rise in ‘scammer participants’ who may pose as autistic people in research studies, particularly when participation incentives are included, such as vouchers. As no incentives were offered for either phase, this potential limitation was reduced. As discussed in Chapter Five, my survey invited autistic adults, whether they were self-identified, professionally assessed or clinically diagnosed; earlier research has not found significant discrepancies between results from self-identified and professionally diagnosed autistic respondents (Charlton *et al*., 2021). Further, research shows that the inclusion of ‘autism trait’ questionnaire items sometimes used to screen out respondents who are not autistic is ineffective; such trait lists are easily obtainable online (Pellicano *et al*., 2023). It would be difficult to tell with any certainty whether data integrity for my study was threatened by potential ‘scammers’ but I aimed to encourage honesty and reduce the risks of accidentally including data from non-eligible respondents through the exclusion criteria presented in Chapter Five. In particular, 17 responses which had not selected ‘yes’ to *Q23: Do you live most or all of the year in the UK*, and 3 responses which had not selected ‘yes’ to *Q24: Are you autistic (including self-identified, professional assessment and/or clinical diagnosis)* were excluded.

2. Ambiguity around alone-time versus time alone

One limitation of the questionnaire which was not flagged by the 26 test-participants during the pilot-test phase was a potential ambiguity around the understanding of *alone-time* as being different from *time alone*. Given that some of the average daily alone-time hours were very high in both 'had' and 'wanted' categories, it seems likely that some of the respondents understood these questions as "how many hours did you have/want alone" rather than "how many hours of *alone-time* did you have/want." It is possible that for people living alone, the concept of alone-time may be understood differently. For instance, some respondents stated that they had and/or wanted an average 24 hours of daily average alone-time, even though the previous questionnaire item included a reminder that sleep hours should not be included. Although these two questions followed immediately after the questionnaire's definition of alone-time it might, on reflection, have been worthwhile clarifying that this question was about alone-time rather than time alone, in order to reduce potential issues with face validity. As discussed in Chapter Seven, future research could also address differences and/or similarities in how autistic adults experience and view alone-time in different living situations (e.g. with families, living alone, supported living etc.).

3. Free-text answers

I included several free-text boxes throughout the questionnaires because I had previously noticed (from social media posts) that autistic people often find that multiple choice questions in surveys do not reflect a suitable range of answers. However, some data was unusable when respondents provided lengthy context-based answers rather than simple numerical values. Since then I have discovered that it is possible to specify that a text box can be set to only allow a numerical value and would use this option in the future. Further, some text-based answers were unusable because they did not answer the question. For instance, *Q6: Which one of the following indoor spaces feels the most important for your wellbeing?* included the text responses, 'home' and some participants answered with an activity. For future research I would add clarification to free text boxes; for instance, instead of the Q6 free-text wording "not listed, please describe" I might write "not listed: please briefly describe what you would most need from an indoor space for it to feel important for your wellbeing:"

An additional limitation related to face-validity is indicated by the sharp drop-off in responses selecting over 5-6 hours for both alone-time had and alone-time wanted. I had expected that the histograms in Chapter Six would more closely resemble a bell-shaped curve for both alone-time had and alone-time wanted, but this was not the case. This may be due to my not offering more options for specified categories. Additional options up to a cut-off point (for instance, in the current study anything over 18 hours was treated as an outlier) may reduce this limitation and so more accurately reflect the respondents' actual and wanted number of alone-time hours.

8.4 Personal reflections

I wrap up my final thesis chapter by considering two concepts which are not often considered in autism research, but which are commonly accepted as community priorities. The first is autistic agency, both personal and collective, and the second is autistic joy.

Autistic people have historically been treated as 'other' and have not been granted either epistemic or physical agency (Botha, 2021a) and, in this position of other, have also been treated as a homogenous group. As such, it is important to note that my PhD research both connects autistic and non-autistic experiences, and highlights individuality. A need for alone-time is not only pertinent to autistic people; research within the general population shows that

> "*social withdrawal immediately following exposure to a stressor can alleviate some of the negative aftereffects of the stressful encounter by returning the individual's mood, arousal, and energy to baseline levels*" (Reptetti, 1992, p.151).

Similarly, Nguyen *et al*. (2018) found that solitude - defined as being alone, without communication, activities or active stimuli - is effective in self-regulating (in particular calming anxiety and anger) for people in the general population, and that the benefits of spending time-alone on a daily basis can 'spill over' into the following week. And so, a need for alone-time - a.k.a. solitude, me-time, downtime or decompression-time - might be considered a universal human need, at least in the English-speaking global North, where these terms are commonly discussed in popular media. However, autistic people, who are widely acknowledged to have lower levels of wellbeing, may have more of a need for this time and space and, due to differences in social and sensory processing, may prefer to use this time differently.

It is important to emphasise that alone-time should never be considered a wellbeing strategy unless decisions around when, how and where alone-time is spent can be made autonomously. Nguyen *et al*. (2018) found that autonomy was important for gaining benefits from this time, but autistic people have not historically been deemed able to make autonomous decisions about improving or maintaining their own wellbeing (Pellicano & Heyworth, 2023). The policy and practice recommendations created by the CAG had an overarching theme of agency and autonomy. While research findings are out of the control of the researcher once they have been published, it is my hope that my research findings are always considered in the context of autistic agency and autonomy.

During the three years since I began my PhD, a new hashtag appeared on social media, #AutisticJoy. While social and sensory environments which do not take autistic social and sensory processing into account are disabling and distressing, preferred social and sensory experiences can have intensely positive emotional and embodied impacts, sometimes to the point of euphoria. People using the hashtag on social media use words or pictures to show or describe fleeting or flow-state emotional experiences through colour combinations or patterns, autistic community, stimming, echolalia, synesthetic experiences, routines and rituals, intense interests, physical activity, collections, being in nature, certain textures, listening to or playing music, spending time with pets, being creative, certain foods or drinks, dancing or alliteration… the list is as long as it is varied. In the first chapter of this thesis I posited that autism can be understood in terms of how the world experiences autistic people, or how autistic people experience the world. When autistic agency and ways-of-being are unsupported, the autistic experience feeds into traditional tragedy narratives; when supported, there is a potential for joy to be an integral part of the autistic experience. I believe that an increase in autistic-led autistic wellbeing research - neurodiversity-informed research which explores positive aspects of autistic mental health - encourages autistic narratives which include Autistic Joy; I hope that my PhD research contributes to this emerging concept.

Appendix A: Interview Schedule

Pseudonym:

Thank you for filling in the online consent form. Before we get started, I would like to remind you that you are free to withdraw now, during, or even straight after this interview, and that you do not have to answer any questions that you don't want to.

I'd also like to remind you that if you need me to stop asking questions, or slow down my questions then just let me know. It's also fine if you need to take a short break.

Are you still happy for us to run this interview?

My questions today will be very similar to the questions on the preparation sheet, but I will be looking for a bit more detail. I will make sure that the interview doesn't run overtime so I might interrupt you sometimes to move onto the next question. Remember that you don't have to answer anything that you aren't comfortable answering, and that you can ask me to explain anything that isn't clear. I will also keep checking that you are happy to continue during the next 45 or so minutes.

Is it ok for me to start recording now?

On your sheet you wrote that you do/don't find it important to spend time alone. Can you tell me more about why this is?

On your sheet you wrote about places you like to be alone. Could you tell me more about these places and why you like to be in them?

Are you ok to go onto the next question?

Could you tell me more about the types of things you like to do when you are alone, and what you find helpful about doing these things?

Could you talk to me more about the spaces you like to be in and why you find these spaces helpful?

Are you happy to continue?

I wonder if you could tell me anything about how you find and create the spaces you like to be in, and how you protect time to be in these spaces, doing the things that are important to you.

Can you tell me how it feels when you don't get to spend time alone, or when you don't get to access the spaces you like to be in?

Last question!

Could you tell me what you think the main benefits are, for you, of spending time alone in the space that suits you?

And finally, we've got __ time left. Is there anything else that you'd like to tell me about?

Thank you again. You've been really helpful.

Would you like me to email you with a summary of this study (probably at the end of this year) to tell you what I found out?

I will be deleting our shared folder in a week or so, so if there's anything you wanted to see or check before then, you'll need to do that in the next few days.

Thank you again

Finish

Appendix B: Qualitative Ethics Application & Approval

This appendix has been removed as it contains personal information

Appendix C: Qualitative Data Management Plan

This is the UWE Bristol research data management plan template.

- The template applies to all research; you are required to fill this in before collecting any data as part of research, or using any data for research.
- You must do this for all research, whether externally or internally funded, as part of scholarship time, or doctoral student research.
- Doctoral students should complete this in conjunction with their DOS/Supervisory team.
- You should update this research data management plan as appropriate, but please always keep prior versions on the Research Governance Record.

Research data management plans for staff and doctoral research must be uploaded to the UWE Research Governance Record. The DOS must do this for doctoral research. This template is available for use by supervisors with taught programme students, but does not, at this point, need to be uploaded to the Research Governance Record (although it is advised that this form should form the basis for a proportionate RDM for all student research).

Please download a fresh copy of the template from the Library's website each time you need to use it; this will ensure that you are using the most up to date version. If you do not use the current version, you may be asked to do it again.

Please refer to the guidance notes before answering each question (accessed by hyperlink from each question).

You may also find the following sources of guidance helpful:

UWE Bristol Research Governance Guidance, including the UWE Bristol Code of Good Research Conduct

UWE Bristol Research Data Protection Standard

UWE Bristol Research Ethics Guidance

The Human Tissue Quality Management System (where appropriate)

The Animal and Animal Welfare Quality Management System (where appropriate). For access to this guidance, please contact the Research Governance Team.

Library Services guidance on research data management

Information Security Toolkit

UWE Project manager name:	Dr Issy Bray
Student name, where applicable:	Florence Neville
Faculty:	Health and Applied Science
Project Title:	Strategies used by autistic individuals to reduce anxiety: an exploratory mixed methods study in the UK (Qualitative component only)

Research Data Management Plan version number:	Click or tap to enter text
Date:	Click or tap to enter a date.

If you have the following reference numbers, please enter them below.

PASS code:	Click or tap here to enter text.
UREC / FREC / AWEC application numbers:	Click or tap here to enter text.
HTSC registration number:	Click or tap here to enter text.
GM registration number:	Click or tap here to enter text.

What data will you collect, create or use? Give a brief description. See Note 1

Data will be collected from fifteen autistic adult participants in the form of:

1. A seven-day structured diary
2. Either a video-interview or a synchronous electronic text-chat interview

Florence Neville (FN), an autistic PhD candidate, will be recruiting autistic adults through social media, and considers that those who are able to independently access social media platforms and then make contact through her UWE email address to show interest in taking part in this study, should be considered as having capacity to consent. (Similar to "Practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants." Nicolaidis *et al*., 2019).

FN does not intend to recruit participants considered vulnerable or potentially vulnerable. However, she recognises that participants may meet one or more of the criteria without her knowledge.

FN will be collecting personal data about how the participants choose to spend time alone, what environments they choose to spend this time in, and what they feel the benefits of this time are. This data will be qualitatively analysed using NVivo software.

Please classify your data here as public, restricted or confidential. See Note 2

The data is confidential. It requires additional protection as it contains personal, sensitive information

How will you collect, create or access the data? See Note 3

1. FN will create a diary template that participants can fill in on a UWE OneDrive file. Each file will only be accessible to herself and the participant.
2. Online video interviews will take place on and be recorded with Microsoft Teams
3. Synchronous text-chat interviews will take place on a UWE OneDrive file which will only be accessible to FN and the participant.

Ethical approval is being sought from UWE Research Ethics

Participant information sheets will be provided for everybody invited to participate. No data will be collected from any participant until they have filled in a consent form via Qualtrics. This form fully describes:

1. how their data will be kept secure, given a pseudonym, and destroyed after the study is completed
2. that my supervisory team will have access to their data, and only after it has been pseudonymised
3. that they can withdraw at any point until identifying data has been removed from their transcripts.

How will the data be stored and backed up at all stages during its life course? See Note 4

FN will assign each participant with a code and pseudonym before their data is transcribed and/or saved. All identifying information will be removed from the data.

1. The diaries will be created and saved in UWE OneDrive, which is regularly backed up.
2. FN will transcribe video interviews directly into a UWE OneDrive document and destroy each audio recording on completion of the transcript.
3. Text-chat interviews will be created and saved in a UWE OneDrive document.

Additionally, the anonymised data will be stored in a password-secure file on NVivo until the study is completed. After this time the file will be destroyed.

All data collection, storage and analysis will take place on a UWE owned, password secure laptop.

How will the data be documented, described and maintained? See Note 5

The OneDrive files (diaries and interview transcripts) will be saved to OneDrive in two separate folders: "F Neville PhD participant diaries" and "F Neville PhD interview transcripts." Files will be identifiable by the pseudonym that FN attributes to each participant. such as: [pseudonym] PhD interview transcript

A minimum of demographic details such as age group, gender and ethnicity will be included with each interview transcript.

How will your data be processed? See Note 6
FN is not collaborating with any third-party organisation or individual or using any third-party data FN will give individuals from her supervisory team access to the data if and when necessary through a shared UWE OneDrive link. The data will be analysed by FN using NVivo software. The NVivo file, which has a software-specific format and is accepted by the UK Data Service, will be password protected.
Does the Data Protection Act (2018) apply to your research? See Note 7
Yes. FN will be working with human participants and the personal data that they will give with informed consent. This data will only be kept for the duration of the study. In the context of the research FN does not consider that the participants are vulnerable. FN has completed the data protection impact assessment screening (attached), and answered "no to all questions" and so is not required to complete a full data protection impact assessment.
Export controls and other legislation and regulation. See Note 8
n/a
What Intellectual Property will be created or used in this research? See Note 9
n/a
What are your plans for long-term preservation and data sharing, where appropriate, and data disposal? See Note 10
FN does not intend to preserve the data and so all data (held on OneDrive and NVivo) will be electronically destroyed on completion of the PhD study as outlined in the participant information sheet and agreed on in the consent form.
Who is responsible for enacting the different elements of the research data management plan? See Note 11
As DoS, Dr Issy Bray has overall responsibility, but FN will be responsible for all day-to-day elements of the research data plan
What resources are needed to deliver the plan, and are these available? See Note 12
FN already has possession of a UWE laptop and a UWE OneDrive account.

Appendix D: Qualitative Participant Information

I am inviting you to take part in online research that I am doing at the University of the West of England, Bristol. This research is funded by the Economic and Social Research Council. Before you agree to take part, it is important to understand why the study is being done and what it will involve. Please read the following information carefully. If you have any questions or would like more information please contact me at Florence2.Neville@live.uwe.ac.uk

Who I am

I am Florence Neville and I am an autistic adult doing research for my PhD. I find that I often need some time alone in a sensory-friendly space. I want to know:

1. How autistic adults choose to spend time they have alone
2. What kind of spaces they like to be alone in
3. How they feel this time and space benefits them

How I will be doing my research

My PhD research will be in two parts. In 2021 I will be interviewing fifteen autistic adults and in 2022 I will be doing an online survey with over 120 other autistic adults. Then I will be writing up the results for my thesis. This year I will be interviewing autistic adults about spending time alone in a sensory-friendly space and I would like you to take part.

If you choose to take part, I will share an online form with you which has a few, short questions about how and where you chose to spend any time you have alone. You will need to complete this form at least a week before the interview to help me focus my interview questions.

You can choose whether I interview you by video link or instant messaging. The interview will take less than one hour and will be about how you choose to spend time you have alone, what spaces you like to be alone in, and how you feel this time and these spaces benefit you.

After the interview I will transcribe (type-up) your answers and remove your name and any information that other people could use to identify you. Then I will look at all the transcripts together to look for common themes or ideas. Next year I will use those themes to create a questionnaire for other autistic people to fill in. This will help me see if lots of people feel the same way about spending time alone in a sensory-friendly space.

The information from the interviews and surveys will help me to write my PhD thesis. I would also like to write a journal article and talk at conferences about the results. I think it is important for non-autistic people to understand what makes autistic people happy. I will make sure that a summary of the results from my studies are easily and freely accessible for autistic communities. If you like, I can email you this summary directly.

Why I would like you to take part

I have invited you to take part in my study because your views and experiences as an autistic adult are important. They will help me understand more about what other autistic people need to feel happy and healthy. Once I know more about how and why autistic adults sometimes choose to spend time alone, in a sensory-friendly environment, I will tell other people about it. These people might be able to make changes that help autistic people in the future.

I would like to interview you if:

- You are autistic (you do not need to have a formal diagnosis)
- You are 18 years old or above
- You live in the United Kingdom

What will happen if you decide to take part

It is important to know that you do not have to take part in this research. You can leave the study at any point until I have transcribed your interview and removed all your personal details. You do not have to give me a reason.

The online form should not take longer than about half an hour to one hour.

The interview will take less than one hour. Because the interview will be online, we will not be meeting in person. You can make sure that the area around you is comfortable for you, and I can do the same for myself.

If you consent to being interviewed online, I will email you clear instructions. I will also ask you if you need anything to make the interview more accessible.

What are the possible risks of taking part?

I don’t think that there are any risks to you from taking part. However, you may feel sad or angry from talking about why you might need time alone, or why a sensory-friendly environment is important to you. I would like to make the interview enjoyable so please tell me if anything we are talking about makes you unhappy.

How I will keep your details confidential

Everything you tell me will be confidential unless I think that you or someone else is in danger. If I think that you or someone else is in danger I will need to tell somebody.

1. When I transcribe your interview, I will remove any information that somebody else could use to identify you.
2. I will also destroy the voice recording or instant-message thread.
3. I will only store your online form and transcript in a password-secure location. Only me and my supervisors will be able to see them.
4. If I quote your words in my study, I will use a pseudonym (a made-up name).

What you can do if you have a concern or complaint

If you have a concern or complaint about me or how I use your information, you can contact my supervisor Issy.Bray@uwe.ac.uk

The project has been reviewed and approved by the research ethics committee at the University of the West of England. If you have any comments, questions or complaints about the ethical conduct of this study you can email them at Researchethics@uwe.ac.uk

What to do if you would like to take part

Please email me at Florence2.Neville@live.uwe.ac.uk with any questions you may have.

Please also refer to the accompanying Privacy Notice before you agree to take part in the research.

I have emailed you two versions of the consent form, one for video interviewing and one for instant-message interviewing. When you have followed the instructions on the version that you choose, I will send you the diary questions and we will arrange a time for me to interview you.

Thank you so much for agreeing to take part in this study, I look forward to speaking with you soon! *Florence Neville, May 2021*

Appendix E: Qualitative Consent

Consent Form for Online Video Interviewing

Project: How do autistic adults choose to spend time alone in a sensory friendly space?

I have emailed you a Participant Information Sheet and a Privacy Notice. This is a copy of the consent form that you completed online. If you are not happy with this procedure you can contact me at Florence2.Neville@live.uwe.ac.uk or you can contact my supervisor at Issy.Bray@uwe.co.uk

Florence Neville, May 2021

- I have read and understood the information in the Participant Information Sheet.
- I have been given the opportunity to ask questions and I am happy with the answers.
- I agree to share an online preparation sheet one week before the interview
- I agree to be interviewed by Florence Neville and for the interview to be audio-recorded.
- I understand that Florence Neville will transcribe (type up) the interview, remove any information that identifies me and store the transcript in a secure, online location.
- I understand that the audio-recording will be destroyed as soon as it is transcribed.
- I give permission for Florence Neville’s supervisor team to read the transcripts.
- I understand that the transcripts will be kept until the study has finished, and then destroyed.
- I understand that if I am quoted in the study, my name will not be used.
- I understand that my participation is voluntary and that until the transcripts have been anonymised I can withdraw without giving a reason.

Your name:

Today’s date:

Consent Form for Instant-Message Interviewing

Project: How do autistic adults choose to spend time alone in a sensory friendly space

I have emailed you a Participant Information Sheet and a Privacy Notice. This is a copy of the consent form that you completed online. If you are not happy with this procedure you can contact me at Florence2.Neville@live.uwe.ac.uk or you can contact my supervisor at Issy.Bray@uwe.co.uk

Florence Neville, May 2021

- I have read and understood the information in the Participant Information Sheet.

- I have been given the opportunity to ask questions and I am happy with the answers.
- I agree to share an online preparation sheet one week before the interview.
- I agree to be interviewed via instant text-chat by Florence Neville.
- I understand that Florence Neville will transcribe (type up) the interview, remove any information that identifies me and store the transcript in a secure, online location.
- I understand that the instant-message chat will be destroyed as soon as it is transcribed.
- I give permission for Florence Neville’s supervisor team to read the transcript.
- I understand that the transcripts will be kept until the study has finished, and then destroyed.
- I understand that if I am quoted in the study, my name will not be used.
- I understand that my participation is voluntary and that until the transcripts have been anonymised I can withdraw without giving a reason.

Your name:

Today’s date:

Appendix F: Qualitative Privacy Notice

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE Bristol) collects, manages and uses your personal data before, during and after you participate in the project, **“How do autistic adults choose to spend time alone in a sensory friendly space?”** ‘Personal data’ means any information relating to an identified or identifiable natural person (the data subject).

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.
- This Privacy Notice should be read in conjunction with the Participant Information Sheet and the Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together “the Data Protection Legislation”). General information on Data Protection law is available from the Information Commissioner’s Office (https://ico.org.uk/).

How do we use your personal data?

We will only process your personal data when the law allows us to. In addition, we will always comply with UWE Bristol’s policies and procedures in processing your personal data. Our lawful basis for using your personal data for research purposes is fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by the Faculty of Health and Applied Sciences research ethics committee, application no: HAS.21.03.128, contact details: researchethics@uwe.ac.uk

The research team adhere to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. Access to your personal data is strictly controlled on a need to know basis and data is stored and transmitted securely using methods such as encryption and access controls for physical records where appropriate.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that those who process your personal information (such as researchers, relevant University administrators and/or third-party processors) are aware of their obligations and responsibilities for the data they have access to.

By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet.

Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your rights and how to exercise them

Under the Data Protection legislation, you have the following **qualified** rights:

1. The right to access your personal data held by or on behalf of the University;
2. The right to rectification if the information is inaccurate or incomplete;
3. The right to restrict processing and/or erasure of your personal data;
4. The right to data portability;
5. The right to object to processing;
6. The right to object to automated decision making and profiling;
7. The right to complain to the Information Commissioner's Office (ICO).

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet or UWE Bristol's research governance manager (researchgovernance@uwe.ac.uk.).

Appendix G: Qualitative Preparation Sheet

Please write your answers in all of the boxes below at least one week before your interview. The box sizes are fixed but you can move my words around or even remove them if you would prefer. Your answers will save automatically, and I will be able to see them when I open the file a few days before your interview.

Name:	*Your real name will **not** be used in the research. I just need to make sure that I use the correct preparation sheet when I interview you!*
Age:	*I will refer to your age if I quote you in the research.*
Gender:	*I need your gender so that I can show the range of genders in my research.*
Ethnicity:	*I need your ethnicity so that I can show the range of ethnicities in my research.*
Your preferred pseudonym:	*This is the name that I will use for you if I quote you in my research. Please make sure that this name reflects your gender and ethnicity.*

For instance, if I was filling this form in I would write:

Name: Flo Neville

Age: 48

Gender: Female

Ethnicity: White British

Your preferred pseudonym: Anne

And if I was quoting myself in the research it might look a bit like this: “Having free time alone is very important to me.” (Anne, 48)

Is having some free time alone important to you? Why is this?	When you have free time alone, are your surroundings important to you? Why is this?

Write a bit about one thing you like to do when you have some free time to yourself.	Write a bit about a place you like to be when you have some free time to yourself.
Write a bit about another thing you like to do when you have some free time to yourself.	Write a bit about another place you like to be when you have some free time to yourself.
Please tell me whether you would like an online video interview or an online text-based interview:	*Video interviews will use Microsoft Teams. You won’t need to download any apps, but you will need a good WiFi connection. I will be able to see and hear you, and you will be able to see and hear me. I will be in a quiet place and nobody will overhear our conversation. You will need to be somewhere quiet where you won’t be interrupted.* *Text interviews will use a shared document like this form that you are filling in. You will see my questions as I write them and I will see your answers as you write them. You won’t need to download any apps but you will need a WiFi connection.*
Please tell me whether you might need anything to make the interview more accessible:	

Please tell me if there is anything you need me to know before the interview:	*Please remember that it's absolutely fine if you want to stim, look away from the camera or even move around the room while I am interviewing you (as long as we can still hear each other/read each other's questions and answers).* *I will not be asking any questions that I think might upset you – in fact, most of my questions will be very similar to the ones on this sheet. But please remember that you do not have to answer any questions that you don't want to. And please tell me during the interview if anything we are talking about is upsetting you so that I can stop asking those questions.*

Appendix H: Codebook and Themes

Code name	**Description**	**Files**	**References**
alleviating anxiety, worry and perseverant thoughts	specific mentions of anxiety together with worry and perseverant thoughts, and how AT helps alleviate these	9	14
awake when others are asleep	present or in the past, deliberate or accidental	7	9
being creative	descriptions of creative activities and why they are helpful	7	11
being in nature	descriptions of being in nature and why it's helpful	12	16
benefits of dissociating	activities helping to dissociate from internal thoughts and emotions	10	21
communicating becomes harder	after lots of being with people it becomes difficult to talk, difficult to listen, might seem like being rude	9	12
creating boundaries	planning TA boundaries and making them clear to others	15	34
escaping into fiction	reading or TV as safe worlds	5	7
feeling connected when alone	connection to animals, places and self	13	23
how overwhelm feels	descriptions of physical feelings when overwhelmed	4	5
immersion and flow state	describing being immersed in something or being in a flow state or mentioning monotropism	12	25
irritation agitation and frustration	feeling irritated, agitated and/or frustrated	6	9
no need to mask when alone	describing masking and why it causes problems	14	25
physical and social distractions	the negative distractions on being able to focus	8	14
processing thoughts and emotions	using time alone to process thoughts and emotions	8	17
recording the details	mindfulness through recording the details	7	10
rituals, routines & repetition	describing rituals, routines and repetitive behaviours	8	15

sensory and social exhaustion	causes and effects of sensory and social exhaustion	8	15
sensory friendly spaces	finding or creating sensory friendly spaces	12	26
socialising must be balanced with AT	wanting to be sociable, but it needs to be balanced with AT	8	13
too much to process	needing to clear the backlog or it's just too much	7	11
walking alone	describing walking alone and its benefits	10	19
wanting to be with others	when being sociable or in the presence of others is wanted	13	20

Reacting to social and sensory overwhelm	**Retreating from social and sensory overwhelm**	**Regulating recovering and recharging**	**Ready to reconnect**
Too much to process How overwhelm feels Physical and social distractions Irritation, agitation and frustration Communicating becomes harder	No need to mask when alone Being in nature Sensory friendly spaces Creating boundaries Awake when others are asleep Rituals, routines and repetition	Recording the details Feeling connected when alone Alleviating anxiety, worry and perseverant thoughts Immersion and flow state Benefits of dissociating Escaping into fiction Being creative Walking alone	Wanting to be with others Socialising must be balanced with alone time

Appendix I: Survey Questions

Table I.1: Questionnaire 1 alone-time questions

Q1: For the first section of this questionnaire I will be asking you about alone-time. Some people refer to alone-time as me-time or decompression-time.

My research so far has shown that alone-time probably needs each of these to be true:

(1) you are in a space where you aren't interrupted or distracted by other people

(2) you are in a space where you feel comfortable

(3) you are able to choose what you do

(Please note that, in this study, alone-time can be spent with animals, and it can be when you are working. It can include napping, but should not include your usual sleep time).

Some people find that they need to be completely alone for alone-time and others can still enjoy alone-time when other people are near them. What do you need?

- *I need to be completely alone with no chance of anyone interrupting or distracting me*
- *I need to be alone where it is unlikely anyone will interrupt or distract me*
- *I don't need to be alone but I need people not to interact with* me

Q2: On average, over the past two weeks, approximately how much alone-time did you have each day? (This might not be the same every day, an average over the past two weeks is fine).

- *No alone time*
- *Up to 1 hour*
- *Between 1 and 2 hours*
- *Between 2 and 3 hours*
- *Between 3 and 4 hours*
- *Between 4 and 5 hours*
- *Between 5 and 6 hours*
- *More than 6 hours – please type in how many hours of alone time you had.*

Q3: On average, over the past two weeks, how much alone-time did you want or need each day? (This might not be the same every day, an average over the past two weeks is fine).

- *No alone time*
- *Up to 1 hour*
- *Between 1 and 2 hours*
- *Between 2 and 3 hours*
- *Between 3 and 4 hours*
- *Between 4 and 5 hours*
- *Between 5 and 6 hours*

More than 6 hours – please type in how many hours of alone time you wanted or needed.

Q4: What do you like to do during your alone-time? (Tick all that apply). Please remember that, in this study, alone-time might include paid work as long as (1) you are in a space where you won't be interrupted or distracted by other people, (2) you are in a space where you feel comfortable and (3) you are able to choose what you do.

- *Read, watch TV or films, listen to audio books, podcasts, music or the radio etc.*
- *Indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc.*
- *Gaming*
- *Creative activities such as software design and coding*
- *Hands-on projects such as DIY, bike maintenance, woodwork etc.*
- *Study an area of interest (books, papers, online etc.)*
- *Jigsaws, crosswords, Sudoku, Wordle etc.*
- *Social media*
- *Mindfulness, yoga, meditation etc.*
- *Stimming*
- *Napping or being still*
- *Exercising (such as cardio, strength or flexibility training)*
- *Outdoor creative activity such as gardening, drawing, photography etc.*
- *Gentle outdoor recreation such as sitting in nature, slow walking etc.*
- *Outdoor physical activity such as long-distance hiking, wild-swimming, biking etc.*
- *Commuting or travel time alone (such as walking, cycling, driving, public transport)*
- *Not listed, please describe*

Q5: Which one of the following feels the most important for your wellbeing? (Tick just one).

- *Read, watch TV or films, listen to audio books, podcasts, music or the radio etc.*
- *Indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc.*
- *Gaming*
- *Creative activities such as software design and coding*
- *Hands-on projects such as DIY, bike maintenance, woodwork etc.*
- *Study an area of interest (books, papers, online etc.)*
- *Jigsaws, crosswords, Sudoku, Wordle etc.*
- *Social media*
- *Mindfulness, yoga, meditation etc.*
- *Stimming*
- *Napping or being still*
- *Exercising (such as cardio, strength or flexibility training)*
- *Outdoor creative activity such as gardening, drawing, photography etc.*
- *Gentle outdoor recreation such as sitting in nature, slow walking etc.*
- *Outdoor physical activity such as long-distance hiking, wild-swimming, biking etc.*
- *Commuting or travel time alone (such as walking, cycling, driving, public transport)*

Not listed, please describe

Q6: Where do you like to spend your alone-time? (Tick all that apply even if there are overlaps).

- *Indoor spaces where you do not have much control over heating, lighting, visuals, noise etc.*

- *Indoor spaces with hardly any sensory distractions (audio, visual etc.)*
- *Indoor spaces that are interesting for your senses (visuals, music, scents etc.)*
- *Indoor spaces that feel cosy*
- *Indoor spaces that feel safe*
- *Indoor spaces that have everything you need for your favourite activities*
- *An outdoor space with hardly any sensory distractions (audio, visual, olfactory etc.)*
- *An outdoor space that is interesting for your senses (audio, visual, olfactory etc.)*
- *Outdoor spaces where there are several or lots of people nearby*
- *Outdoor spaces where there are no or very few people nearby*
- *Maintained natural or rural outdoor spaces (such as local parks or public/private gardens)*
- *Natural or rural outdoor spaces (such as National Parks, woodlands or beaches*
- *Urban spaces (such as city streets or busy shopping areas)*
- *Familiar outdoor spaces (places you know well)*
- *Unfamiliar outdoor spaces (places you don't know well)*
- *Not listed, please describe*

Q7: Which one of the following indoor spaces feels the most important for your wellbeing? (Tick just one).

- *Indoor spaces where you do not have much control over heating, lighting, visuals, noise etc.*
- *Indoor spaces with hardly any sensory distractions (audio, visual etc.)*
- *Indoor spaces that are interesting for your senses (visuals, music, scents etc.)*
- *Indoor spaces that feel cosy*
- *Indoor spaces that feel safe*
- *Indoor spaces that have everything you need for your favourite activities*
- *Not listed, please describe*

Q8: Which one of the following outdoor spaces feels the most important for your wellbeing? (Tick just one).

- *An outdoor space with hardly any sensory distractions (audio, visual, olfactory etc.)*
- *An outdoor that is interesting for your senses (audio, visual, olfactory etc.)*
- *Outdoor spaces where there are several or lots of people nearby*
- *Outdoor spaces where there are no or very few people nearby*
- *Maintained natural or rural outdoor spaces (such as local parks or public/private gardens)*
- *Natural or rural outdoor spaces (such as National Parks, woodlands or beaches*
- *Urban spaces (such as city streets or busy shopping areas)*
- *Familiar outdoor spaces (places you know well)*
- *Unfamiliar outdoor spaces (places you don't know well)*
- *Not listed, please describe*

Table I.2: Questionnaire 2 alone-time questions

Q1: On average, over the past two weeks, approximately how much alone-time did you have each day?

(This might not be the same every day, an average over the past two weeks is fine).

- *No alone time*
- *Up to 1 hour*
- *Between 1 and 2 hours*

- *Between 2 and 3 hours*
- *Between 3 and 4 hours*
- *Between 4 and 5 hours*
- *Between 5 and 6 hours*
- *More than 6 hours – please type in how many hours of alone time you had.*

Q2: On average, over the past two weeks, how much alone-time did you want or need each day? (This might not be the same every day, an average over the past two weeks is fine).

- *No alone time*
- *Up to 1 hour*
- *Between 1 and 2 hours*
- *Between 2 and 3 hours*
- *Between 3 and 4 hours*
- *Between 4 and 5 hours*
- *Between 5 and 6 hours*

More than 6 hours – please type in how many hours of alone time you wanted or needed.

Table I.3: The Warwick-Edinburgh Mental Well-Being Scale (WEMWBS) used in Questionnaire 1 and Questionnaire 2

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of each over the last 2 weeks

Statements	**None of the time**	**Rarely**	**Some of the time**	**Often**	**All of the time**
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5

I’ve been feeling cheerful	1	2	3	4	5

Table I.4: The Short Warwick-Edinburgh Mental Well-Being Scale for comparison (SWEMWBS)

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of each over the last 2 weeks

Statements	**None of the time**	**Rarely**	**Some of the time**	**Often**	**All of the time**
I’ve been feeling optimistic about the future	1	2	3	4	5
I’ve been feeling useful	1	2	3	4	5
I’ve been feeling relaxed	1	2	3	4	5
I’ve been dealing with problems well	1	2	3	4	5
I’ve been thinking clearly	1	2	3	4	5
I’ve been feeling close to other people	1	2	3	4	5
I’ve been able to make up my own mind about things	1	2	3	4	5

Table I.5: Questionnaire 1 demographic questions (these were not repeated for Questionnaire 2)

- Q23: Do you live most or all of the year in the UK
- *Yes*
- *No*
- *Not applicable*

Q24: Are you autistic (including self-identified, professional assessment and/or clinical diagnosis).

- *Yes*
- *No*
- *Not applicable*

Q25: Are you filling in this questionnaire on behalf of someone else who is autistic

- *Yes*
- *No*
- *Not applicable.*

Q25: If you are completing this questionnaire on behalf of someone else, did you consult with them for each answer?

- *Yes*
- *No*
- *Not applicable*

Q26: Which of the following best describes your gender?

- *Female*
- *Male*
- *Non-binary*
- *Not listed, please describe*
- *Prefer not to answer*

Q27: How old are you?

- *17 or under*
- *18-30*
- *31-40*
- *41-50*
- *51-60*
- *81-70*
- *71-80*
- *81 or over*

Q28: What is your ethnic background?

- *Asian / Asian British*
- *Black / African / Caribbean / Black British*
- *Mixed / multiple ethnic*
- *White*
- *Not listed, please describe*
- *Prefer not to answer*

Q29: Please select the highest level of education you have attained.

- *GCSE / O level or equivalent*
- *A level or equivalent*
- *Trade, technical or vocational training*
- *Bachelors degree or equivalent*
- *Postgraduate qualification*
- *Not listed, please describe*
- *Prefer not to say*

Appendix J: Quantitative Ethics Application & Approval

This appendix has been removed as it contains personal information

Appendix K: Quantitative Data Management Plan

This is the UWE Bristol research data management plan template.

- The template applies to all research; you are required to fill this in before collecting any data as part of research, or using any data for research.
- You must do this for all research, whether externally or internally funded, as part of scholarship time, or doctoral student research.
- Doctoral students should complete this in conjunction with their DOS/Supervisory team.
- You should update this research data management plan as appropriate, but please always keep prior versions on the Research Governance Record.

Research data management plans for staff and doctoral research must be uploaded to the UWE Research Governance Record. The DOS must do this for doctoral research. This template is available for use by supervisors with taught programme students, but does not, at this point, need to be uploaded to the Research Governance Record (although it is advised that this form should form the basis for a proportionate RDM for all student research).

Please download a fresh copy of the template from the Library's website each time you need to use it; this will ensure that you are using the most up to date version. If you do not use the current version, you may be asked to do it again.

Please refer to the guidance notes before answering each question (accessed by hyperlink from each question).

You may also find the following sources of guidance helpful:

UWE Bristol Research Governance Guidance, including the UWE Bristol Code of Good Research Conduct

UWE Bristol Research Data Protection Standard

UWE Bristol Research Ethics Guidance

The Human Tissue Quality Management System (where appropriate)

The Animal and Animal Welfare Quality Management System (where appropriate). For access to this guidance, please contact the Research Governance Team.

Library Services guidance on research data management

Information Security Toolkit

UWE Project manager name:	Dr Issy Bray
Student name, where applicable:	Florence Neville
Faculty:	Health and Applied Science
Project Title:	Strategies used by autistic adults to improve wellbeing: an exploratory mixed methods study in the UK

Research Data Management Plan version number:	V2
Date:	08/08/2022

If you have the following reference numbers, please enter them below.	
PIMS REF number:	Click or tap here to enter text.
URESC / FREC / AWESC application numbers:	Click or tap here to enter text.
HTSC registration number:	Click or tap here to enter text.
GM registration number:	Click or tap here to enter text.

Q1. What data will you collect, create or use? Give a brief description. See Note 1

Qualitative component only (data collection and analysis already completed):
Data was collected from sixteen autistic adult participants in the form of:

1. A pre-interview preparation sheet
2. Either a video-interview or a synchronous electronic text-chat interview

Florence Neville (FN), an autistic PhD candidate, recruited autistic adults through social media, and considered that those who were able to independently access social media platforms and then make contact through her UWE email address to show interest in taking part in this study, should be considered as having capacity to consent. (Similar to "Practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants." Nicolaidis et al., 2019).

FN did not intend to recruit participants considered vulnerable or potentially vulnerable. However, she recognised that participants may have met one or more of the criteria without her knowledge.

FN collected personal data about how the participants choose to spend time alone, what environments they choose to spend this time in, and what they felt the benefits of this time were. This data was qualitatively analysed using NVivo software.

Quantitative component only (Data not yet collected):
To gather information about how and where autistic adults choose to spend time alone, and the potential benefits of these chosen times and spaces, quantitative data will be collected from at least 250 autistic adult participants via a Qualtrics questionnaire. Participants will fill out two questionnaires, four weeks apart. Ethical approval for this study has been granted, ref: HAS.22.05.108

Florence Neville (FN), an autistic PhD candidate, will be recruiting autistic adults through social media, and considers that those who are able to independently access social media platforms and then follow a link to complete a survey, should be considered as having capacity to consent. (Similar to "Practice-based guidelines for the inclusion of autistic adults in research as co-researchers and study participants." Nicolaidis et al., 2019).

FN does not intend to recruit participants considered vulnerable or potentially vulnerable. However, she recognises that participants may meet one or more of the criteria without her knowledge.

FN will be collecting data about:

1. how the participants choose to spend time alone
2. what environments they choose to spend time alone in
3. their wellbeing, using the Warwick-Edinburgh Mental Health and Wellbeing Scale (WEMWBS)
4. standard demographic information

Data will be analysed using SPSS statistical software.

Q2. How will you collect, create or access the data? See Note 2

Qualitative component only (data collection and analysis already completed):
1. FN created a pre-interview preparation sheet that participants could fill in on a UWE OneDrive file. Each file was only be accessible to herself and the participant.
2. Online video interviews took place on and were recorded with Microsoft Teams
3. Synchronous text-chat interviews took place on a UWE OneDrive file which was only accessible to FN and the participant.

Ethical approval was granted from UWE Research Ethics. UWE REC REF No: HAS.22.05.108

Participant information sheets were provided for everybody invited to participate. No data was collected from any participant until they had filled in a consent form via Qualtrics. This form fully described:

1. how their data would be kept secure, given a pseudonym, and destroyed after completion of the study
2. that my supervisory team would have access to their data, and only after it was pseudonymised
3. that they could withdraw at any point until identifying data was removed from their transcripts.

Quantitative component only (data not yet collected):
Data will be collected from participants using the Qualtrics platform.

Participant information will be provided at the beginning of each questionnaire (which includes a link to the research privacy notice) and will be followed by a consent form.

These elements make it clear that participation is voluntary, that their information will be anonymous, that if they do not submit their answers at the end of the questionnaire, then their data will not be used, and that the research findings will be shared with both academic and non-academic communities. The data itself will not be shared with or reused by anyone else.

In order to email a link to the second questionnaire, participants will click on a link at the end of Questionnaire 1 (Q1) to a separate survey (Q1.2) that only asks for their email address. These email addresses will be added to files listed by date on FN's OneDrive, in a folder marked Questionnaire Emails. Four weeks after participants provide their email address, participants will be emailed (blind copy) with an anonymous link to Q2, with a reminder sent out the following week. In this way, email addresses will be kept entirely separate from their data.

In order to collate participant's first and second surveys while protecting their anonymity, participants will be guided through creating an identifier code in Q1 asking for the first two letters of their birth month, the last two letters of their surname and the last two numbers of their mobile number (or landline if they do not have a mobile number). They will be asked the same questions in Q2.

Q3. Please classify your data here as public, restricted or confidential. See Note 3

The data is confidential. It requires additional protection as it contains personal, sensitive information.

Q4. How will the data be stored and backed up at all stages during its life course? See Note 4

Qualitative component only (data collection and analysis already completed):

FN assigned each participant with a code and pseudonym before their data was transcribed and/or saved. All identifying information was removed from the data.

1. The pre-interview preparation sheets were created and saved in UWE OneDrive, which is regularly backed up.
2. FN transcribed video interviews directly into a UWE OneDrive document and destroyed each audio recording on completion of the transcript.
3. Text-chat interviews were created and saved in a UWE OneDrive document.

Additionally, the anonymised data is stored in a password-secure file on NVivo until the study is completed. After this time the file will be destroyed.

Quantitative component only (data not yet collected):
All data collection, storage and analysis will take place on a UWE owned, password secure laptop.

The data will be stored on the Qualtrics platform, which is password secure, and on OneDrive for Business which is secure and automatically backed up. Additionally, email addresses will be stored in a OneDrive folder (as described in question 2). Once the study has been completed, all data will be electronically destroyed.

Q5. How will the data be documented, described and maintained? See Note 5

Qualitative component only (data collection and analysis already completed):
The OneDrive files (diaries and interview transcripts) were saved to OneDrive in two separate folders:” F Neville PhD preparation sheets” and “F Neville PhD interview transcripts.” Files were identifiable by the pseudonym that FN attributed to each participant. such as: [pseudonym] PhD interview transcript

A minimum of demographic details - age group, gender and ethnicity - were included with each interview transcript.

Quantitative component only (data not yet collected):
Each copy of the data set will include version number in the file name. A separate document will describe the survey questions and coding used for each question. Data will be cleaned before analysis.

Q6. How will your data be processed? See Note 6

FN is not collaborating with any third-party organisation or individual or using any third-party data.

Qualitative component only (data collection and analysis already completed):
FN gave individuals from her supervisory team access to the data only when necessary through a shared UWE OneDrive link.

The data was analysed by FN using NVivo software. The NVivo file, which has a software-specific format and is accepted by the UK Data Service, is password protected.

Quantitative component only (data not yet collected):
The data will be processed in Qualtrics and SPSS on a secure, password secure UWE laptop.

Q7. Does the Data Protection Act (2018) apply to your research? See Note 7

Yes. FN will be collecting data from human participants with informed consent. This data will only be kept for the duration of the study.

In the context of the research FN does not consider that the participants are vulnerable. FN has completed the data protection impact assessment screening (attached), and answered "no to all questions" and so is not required to complete a full data protection impact assessment.

Q8. Export controls and other legislation and regulation. See Note 8

n/a

Q9. What Intellectual Property will be created or used in this research? See Note 9

n/a

Q10. What are your plans for long-term preservation and data sharing, where appropriate, and data disposal? See Note 10

FN does not intend to preserve the data and so all data (held on Qualtrics, OneDrive, NVivo and SPSS) will be electronically destroyed on completion of the PhD study as outlined in the participant information sheet and agreed on in the consent form.

Q11. Who is responsible for enacting the different elements of the research data management plan? See Note 11

As DoS, Dr Issy Bray has overall responsibility, but FN is responsible for all day-to-day elements of the research data plan

Q12. What resources are needed to deliver the plan, and are these available? See Note 12

FN already has possession of a UWE laptop and a UWE OneDrive account.

Appendix L: Quantitative Participant Information

Alone-time for autistic adults: first questionnaire

Thank you for your interest in taking part in this study. My name is Flo Neville and I am an autistic researcher studying for a PhD at the University of the West of England (UWE). My research is on how and where other autistic adults use ‘alone-time’ to improve their wellbeing.

I have a team of three autistic adults who advise me on making sure my research is relevant to and respectful of a wide range of autistic people. I also have four academic supervisors led by Dr Isabelle Bray.

My research is funded by the Economic and Social Research Council and has been given ethical approval by UWE’s Faculty of Health and Applied Sciences [ref: HAS.22.05.108].

If you are an autistic adult (aged 18 or over) who lives in the UK, I invite you to take part in two short questionnaires. Filling in these questionnaires (one now and the other in two weeks) should not take you more than about fifteen minutes in total.

In both these questionnaires I will ask you questions about how and where you choose to spend ‘alone-time', and I will ask you questions about your wellbeing in the last two weeks. In the first questionnaire there will also be a few basic background information questions.

My research will be used to explain why it might be important for autistic people to have uninterrupted time to relax and regulate in the way that they choose and in the places that they choose.

I will tell people about my study findings through journals and conferences, and I will make sure that my findings are easily and freely available online for autistic people and their allies.

Please note that there are no payments or prizes for taking part in this research. I do not think that you will find taking part in this survey upsetting, but if you are distressed in any way please contact one of the helplines (including text and webchat services) suggested on mind.org.uk

Please read the research privacy notice: https://florenceneville.com/privacy-notice-for-research-participants/ If you have any questions about how to take part in this research, or if you have any concerns about this research please contact me: Florence2.Neville@live.uwe.ac.uk

Alone-time for autistic adults: second questionnaire

Thank you for coming back to take part in the second part of this study. Just to remind you, my name is Flo Neville and I am an autistic researcher studying for a PhD at the University of the West of England (UWE). My research will be used to explain why it might be important for autistic people to have uninterpreted time to relax and regulate in the way that they choose and in the places that they choose.

You may be glad to know that this questionnaire will be much shorter than the previous one. Hopefully it won't take you more than five minutes.

In this questionnaire I will ask you 2 questions about your ‘alone-time’ in the last two weeks (since the last questionnaire), and I will ask you to answer 14 questions about your wellbeing in the last two weeks.

As before, please note that there are no payments or prizes for taking part in this research. I do not think that you will find taking part in this survey upsetting, but if you are distressed in any way please contact one of the helplines (including text and webchat services) suggested on mind.org

Please read the research privacy notice: https://florenceneville.com/privacy-notice-for-research-participants/ If you have any questions about how to take part in this research, or if you have any concerns about this research please contact me: Florence2.Neville@live.uwe.ac.uk

Appendix M: Quantitative Consent

I will only use the information you give me if I have your consent to do so. To give your consent please click yes for each of the following five statements AND click the submit button at the end of the questionnaire.

1. I am happy with the information you have given me
2. I know that this questionnaire is anonymous and that nobody will be able to identify me from my answers
3. I know that I do not have to take part in this study
4. I know that if I do not click the blue ‘submit’ button at the end of the questionnaire my information will not be used
5. I am happy for the anonymous answers I give you to be shared with academic communities (e.g. papers and conferences) and non-academic communities (e.g. social media, blog posts and workshops)

all questions were offered as a matrix style questionnaire item with options to click either* ***yes* *or* ***no*** *for each answer*

Appendix N: Quantitative Privacy Notice

Purpose of the Privacy Notice

This privacy notice explains how the University of the West of England, Bristol (UWE Bristol) collects, manages and uses your personal data before, during and after you participate in the project, **"How do autistic adults choose to spend time alone in a sensory friendly space?"** 'Personal data' means any information relating to an identified or identifiable natural person (the data subject).

This privacy notice adheres to the General Data Protection Regulation (GDPR) principle of transparency. This means it gives information about:

- How and why your data will be used for the research;
- What your rights are under GDPR; and
- How to contact UWE Bristol and the project lead in relation to questions, concerns or exercising your rights regarding the use of your personal data.
- This Privacy Notice should be read in conjunction with the Participant Information Sheet and the Consent Form provided to you before you agree to take part in the research.

Why are we processing your personal data?

UWE Bristol undertakes research under its public function to provide research for the benefit of society. As a data controller we are committed to protecting the privacy and security of your personal data in accordance with the (EU) 2016/679 the General Data Protection Regulation (GDPR), the Data Protection Act 2018 (or any successor legislation) and any other legislation directly relating to privacy laws that apply (together "the Data Protection Legislation"). General information on Data Protection law is available from the Information Commissioner's Office (https://ico.org.uk/).

How do we use your personal data?

We will only process your personal data when the law allows us to. In addition, we will always comply with UWE Bristol's policies and procedures in processing your personal data. Our lawful basis for using your personal data for research purposes is fulfilling tasks in the public interest, and for archiving purposes in the public interest, for scientific or historical research purposes.

We will always tell you about the information we wish to collect from you and how we will use it. We will not use your personal data for automated decision making about you or for profiling purposes.

Our research is governed by robust policies and procedures and, where human participants are involved, is subject to ethical approval from either UWE Bristol's Faculty or University Research Ethics Committees. This research has been approved by the Faculty of Health and Applied Sciences research ethics committee, application no: HAS.22.05.108, contact details: researchethics@uwe.ac.uk

The research team adhere to the Ethical guidelines of the British Educational Research Association (and/or the principles of the Declaration of Helsinki, 2013) and the principles of the General Data Protection Regulation (GDPR).

For more information about UWE Bristol's research ethics approval process please see our Research Ethics webpages at www1.uwe.ac.uk/research/researchethics

What data do we collect?

The data we collect will vary from project to project. Researchers will only collect data that is essential for their project. The specific categories of personal data processed are described in the Participant Information Sheet provided to you with this Privacy Notice.

Who do we share your data with?

We will only share your personal data in accordance with the attached Participant Information Sheet and your consent.

How do we keep your data secure?

We take a robust approach to protecting your information with secure electronic and physical storage areas for research data with controlled access. Access to your personal data is strictly controlled on a need to know basis and data is stored and transmitted securely using methods such as encryption and access controls for physical records where appropriate.

Alongside these technical measures there are comprehensive and effective policies and processes in place to ensure that those who process your personal information (such as researchers, relevant University administrators and/or third-party processors) are aware of their obligations and responsibilities for the data they have access to.

By default, people are only granted access to the information they require to perform their duties. Mandatory data protection and information security training is provided to staff and expert advice available if needed.

How long do we keep your data for?

Your personal data will only be retained for as long as is necessary to fulfil the cited purpose of the research. The length of time we keep your personal data will depend on several factors including the significance of the data, funder requirements, and the nature of the study. Specific details are provided in the attached Participant Information Sheet.

Anonymised data that falls outside the scope of data protection legislation as it contains no identifying or identifiable information may be stored in UWE Bristol's research data archive or another carefully selected appropriate data archive.

Your Rights and how to exercise them

Under the Data Protection legislation, you have the following **qualified** rights:

8. The right to access your personal data held by or on behalf of the University;
9. The right to rectification if the information is inaccurate or incomplete;
10. The right to restrict processing and/or erasure of your personal data;
11. The right to data portability;
12. The right to object to processing;
13. The right to object to automated decision making and profiling;
14. The right to complain to the Information Commissioner's Office (ICO).

We will always respond to concerns or queries you may have. If you wish to exercise your rights or have any other general data protection queries, please contact UWE Bristol's Data Protection Officer (dataprotection@uwe.ac.uk).

If you have any complaints or queries relating to the research in which you are taking part please contact either the research project lead, whose details are in the attached Participant Information Sheet or UWE Bristol's research governance manager (researchgovernance@uwe.ac.uk.).

Appendix O: Changes to Survey after Pilot Testing

So that I can link up this questionnaire with the second questionnaire (in four weeks) I need you to create a unique, six-digit identifier code.

To create this code please fill in the following (I will ask you the same questions when you begin the second questionnaire):

The first two letters of your birth month (e.g. if your birth month is January write in J A) _ _

The last two letters of your surname _ _

The last two numbers of your mobile number (or landline if you do not have a mobile number) _ _

As the testers created and re-created codes with no apparent problems, this item was unchanged

For the first section of this questionnaire I will be asking you about alone-time. Some people might refer to alone-time as me-time or decompression-time. In this study 'alone-time' means time when you have all three of these:

a) you are in a space where you won't be interrupted or distracted by other people
b) you are in a space where you feel comfortable
c) you are able to choose what you do

(Please note that, in this study, alone-time can be spent with animals)

Following feedback that testers interpreted this description differently, a clarification survey item was added (see Appendix I, Q1)

Clarification was added that alone-time should not include sleep time

Clarification was added that alone-time could include work time if the above criteria (a-c) were met

On average, over the past two weeks, approximately how much alone-time did you have each day? (This may not be the same every day, an average over the past two weeks is fine).

1. No alone time
2. Up to 1 hour
3. 1-2 hours
4. 2-3 hours
5. 3-4 hours
6. 4-5 hours

7. 5-6 hours
8. More than 6 hours – please type in how many hours of alone time you had

This item was unchanged

On average, over the past two weeks, how much alone-time did you want or need each day? (This may not be the same every day, an average over the past two weeks is fine).

1. Less than an hour
2. 1-2 hours
3. 2-3 hours
4. 3-4 hours
5. 4-5 hours
6. 5-6 hours
7. More than 6 hours – please type in how many hours of alone-time you wanted or needed

Added: no alone-time

What did you do during any alone-time over the past two weeks? (tick all that apply). Please remember that, in this study, alone-time can include paid work as long as (1) you are in a space where you won't be interrupted or distracted by other people (2) you are in a space where you feel comfortable and (3) you are able to choose what you do.

- read / watch TV or films / listen to audio books, podcasts, music or the radio
- indoor creative activities including art, design, writing, photography, playing an instrument, crafting etc.
- gaming
- online or computer based creative activities including software design, coding, etc.
- hands-on projects such as DIY, bike maintenance, woodwork etc.
- study an area of interest (books, papers, online etc.)
- jigsaws, crosswords, sudoku, wordle etc.
- social media
- mindfulness, yoga, meditation etc.
- stimming
- napping or being still
- exercising (such as cardio, strength or flexibility training)
- outdoor recreation such as gardening, sitting in nature, slow walking, photography etc.
- outdoor physical activity such as long-distance hiking, wild-swimming, biking etc.
- I did not have any alone-time **if no alone-time – skip questions up until WEBWMS*

- not listed, please describe

Question was changed to "what do you like to do during your alone-time"

Exercising was changed to indoor exercising

Online or computer based creative activities including software design, coding etc. changed to creative activities such as software design, coding etc.

Added: outdoor spaces that are interesting for your senses

Added: outdoor creative activity such as gardening, drawing, photography etc

Added: driving

Of the activities that you did in the past two weeks, which **three** were most important to you? Please write the number 1 in the box for the activity that was the most important to you, the number 2 in the box that was the second most important to you, and the number 3 in the box that was the third most important to you.

repeat the list above

(Qualtrics has an option to move single items around to arrange a preferred order, but this process isn't always accessible for everyone.)

Question changed to: Which one of the following feels the most important for your wellbeing? (Tick just one).

Where did you spend your alone-time in the past two weeks? (tick all that apply). Please remember that, in this study, alone-time must be in a place that you *want* to be in.

I understand that there will be overlaps

- an indoor space where you had control over heating, lighting, visuals, noise etc.
- an indoor space where you did not have much control over heating, lighting, visuals, noise etc.
- an indoor space with hardly any sensory distractions (audio, visual etc.)
- an indoor space that was interesting for your senses (visuals, music, scents etc.)
- an indoor space that felt cosy
- an indoor space that felt safe
- an indoor space that had everything you needed for your favourite activities
- an outdoor space where there were several or lots of other people nearby
- an outdoor space where there were no or very few people nearby

- a maintained natural or rural outdoor space (such as a local park or a public/private garden)
- a natural or rural outdoor space (such as a National Park, woodland or a beach)
- an urban space (such as city streets or a busy shopping area)
- a familiar outdoor space (somewhere you know well)
- an unfamiliar outdoor space (somewhere you don't know well)
- not listed, please describe

Item question changed to: Where do you like to spend your alone-time? (Tick all that apply even if there are overlaps).

Of the indoor spaces that you spent your time-alone during the past two weeks, which **three** were most important to you? Please write the number 1 in the box for the activity that was the most important to you, the number 2 in the box that was the second most important to you, and the number 3 in the box that was the third most important to you.

Repeat list above from indoor options including

- not listed, please describe
- I did not have any alone-time indoors

Item question changed to: Which one of the following indoor spaces feels the most important for your wellbeing? (Tick just one).

Of the outdoor spaces that you spent your time-alone in the past two weeks, which **three** were most important to you? Please write the number 1 in the box for the activity that was the most important to you, the number 2 in the box that was the second most important to you, and the number 3 in the box that was the third most important to you.

Repeat list above from outdoor options including

- not listed, please describe
- I did not have any alone-time outdoors

Item question changed to: Which one of the following outdoor spaces feels the most important for your wellbeing? (Tick just one).

The Warwick-Edinburgh Mental Well-being Scale (WEMWBS)

Below are some statements about feelings and thoughts.

Please tick the box that best describes your experience of each over the last 2 weeks

STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been feeling interested in other people	1	2	3	4	5
I've had energy to spare	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling good about myself	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been feeling confident	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5
I've been feeling loved	1	2	3	4	5
I've been interested in new things	1	2	3	4	5
I've been feeling cheerful	1	2	3	4	5

No changes were made to the WEMWBS

For this last section of the questionnaire I would like you to answer a few demographic questions. Your answers won't be used in my analysis, but they will help me see whether the needs and experiences of a wide range of people are represented.

Starred* answers determine if that questionnaire is automatically discarded

Are you autistic?

- yes/no

If no – are you completing this questionnaire on behalf of somebody else who is autistic?

- yes/no

If you are completing this questionnaire on behalf of somebody else who is autistic, did they consent and did you directly consult with them for each answer?

- yes/no*

Clarification added: are you autistic (including self-identified, professional assessment and/or clinical diagnosis).

Which of the following best describes your gender?

1. Female
2. Male
3. Non-binary
4. Not listed, please describe
5. Prefer not to answer

No changes were made to this item

How old are you?

1. 17 or under*
2. 18-30
3. 31-40
4. 41-50
5. 51-60
6. 61-70
7. 71-80
8. 80 or over

No changes were made to this item

Do you live in the UK?

- yes/no*

No changes were made to this item

What is your ethnic background?

White

1. English / Welsh / Scottish / Northern Irish / British
2. Irish
3. Gypsy or Irish Traveller
4. Not listed, please describe

Mixed / Multiple ethnic groups

1. White and Black Caribbean
2. White and Black African
3. White and Asian
4. Not listed, please describe

Asian / Asian British

1. Indian
2. Pakistani
3. Bangladeshi
4. Chinese
5. Not listed, please describe

Black / African / Caribbean / Black British

1. African
2. Caribbean
3. Not listed, please describe

Not listed ethnic group

1. Arab
2. Not listed, please describe

Prefer not to answer

The subcategories were excluded, but this was not as a result of pilot testing

Please select the highest level of education you have attained

1. GCSE / O level or equivalent
2. A level or equivalent
3. Trade, technical or vocational training
4. Bachelor’s degree or equivalent
5. Postgraduate qualification
6. Not listed, please describe

7. Prefer not to say

This item was not changed

Appendix P: Invitation and Reminder

Invitation

Dear participant

Thank you for filling in my online questionnaire about alone-time, two weeks ago. I am very grateful for your help with my research. Once the study is finished, I will post the results on AutismHWB.com

You kindly gave me your email address so I could invite you to fill in my second questionnaire. This questionnaire should only take around five minutes to complete. Please could you do this in the next few days?

Here is the link to the second questionnaire:
https://qfreeaccountssjc1.az1.qualtrics.com/jfe/form/SV_ef9u7kR0qBCPllk

Best wishes

Flo

Reminder

Dear participant

If you have already filled in my second questionnaire about alone-time, please accept my thanks and ignore this email!

If you haven’t yet filled it in, it would be great if you’d do that today. Here is the link:
https://qfreeaccountssjc1.az1.qualtrics.com/jfe/form/SV_ef9u7kR0qBCPllk

Please be assured that I will not email again, and I will now remove your email address from my records.

Thank you again and very best wishes

Flo

Appendix Q: Additional Figures for Chapter Six

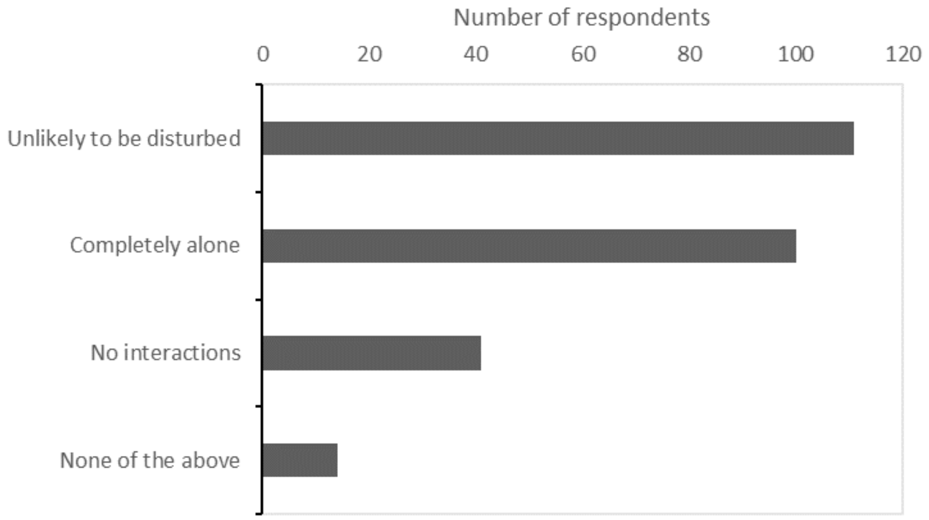


Figure Q.1: Respondents' requirements for not feeling interrupted or distracted by other people

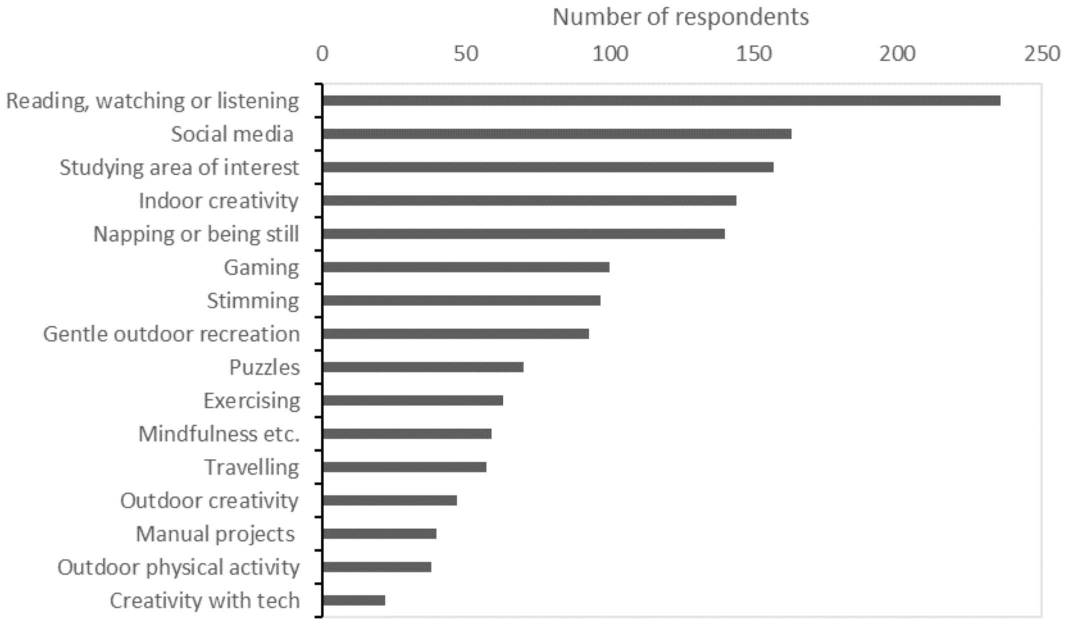


Figure Q.2: Activities enjoyed during alone-time (with category labels shortened for convenience)

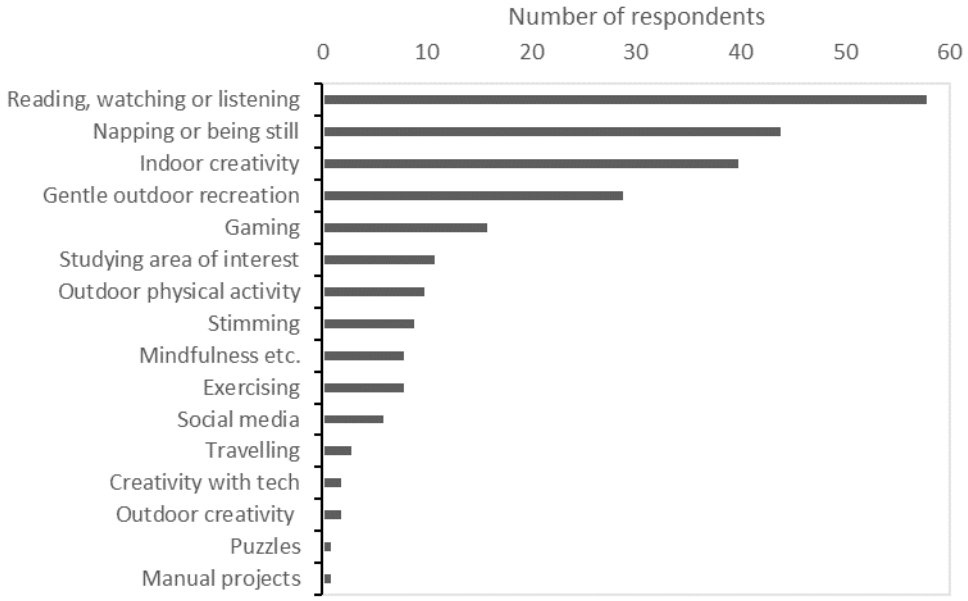


Figure Q.3: Most important alone-time activities for wellbeing (with category labels shortened for convenience)

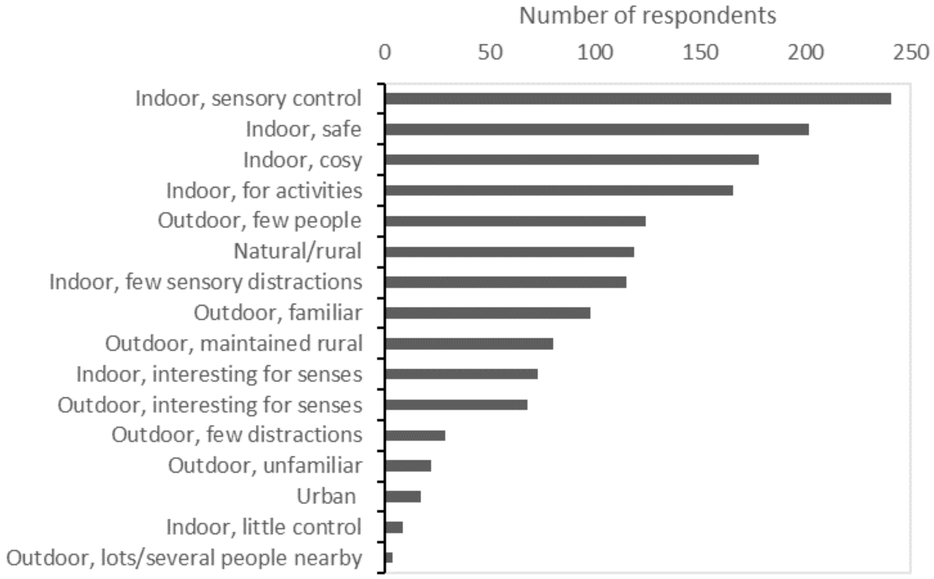


Figure Q.2: Most popular alone-time spaces (with category labels shortened for convenience)

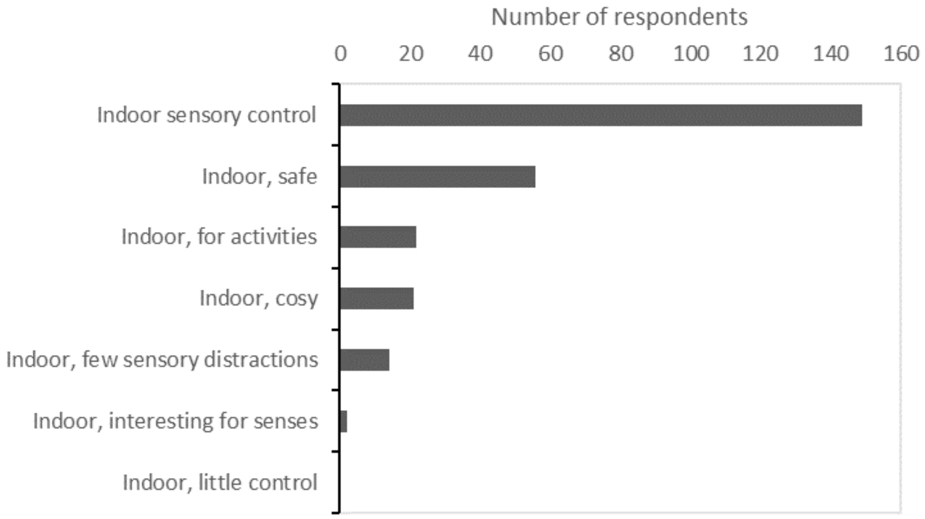


Figure Q.6: Most important indoor spaces for wellbeing (with category labels shortened for convenience)

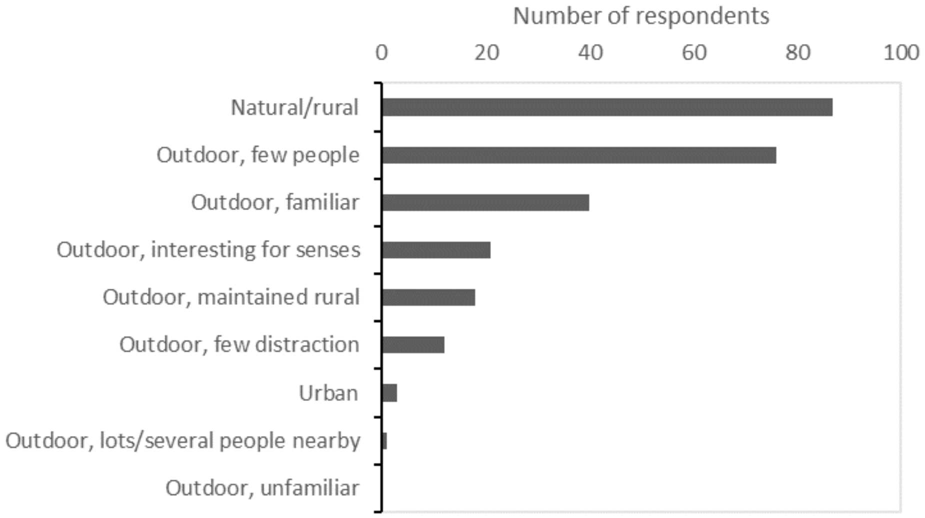


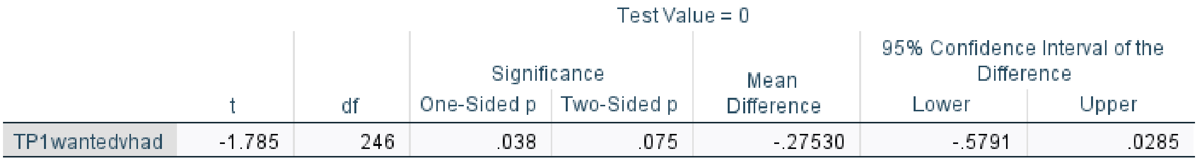
Figure Q.7: Most important outdoor spaces for wellbeing (with category labels shortened for convenience)

Appendix R: SPSS Output for Statistical Tests

RQ3.1

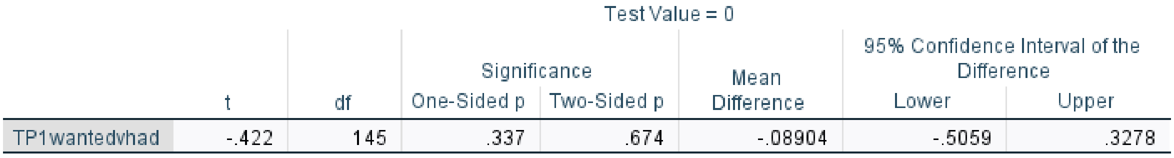
- H_0: There is no difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point
- H_1: There is a difference between the number of alone-time hours had and the number of alone-time hours wanted at each time point

Table R.1: One-sample test on the exposure variable at time point 1



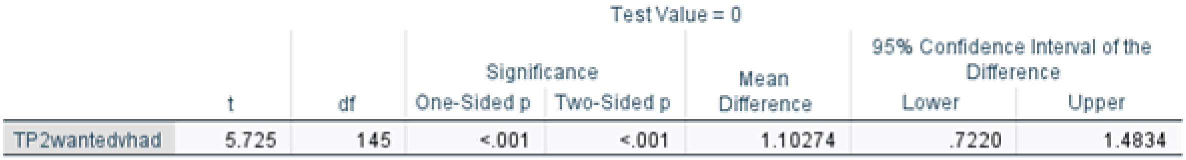
	Test Value = 0						
			Significance			95% Confidence Interval of the Difference	
	t	df	One-Sided p	Two-Sided p	Mean Difference	Lower	Upper
TP1wantedvhad	-1.785	246	.038	.075	-.27530	-.5791	.0285

Table R.2: Sensitivity test of one-sample test on the exposure variable at time point 1



	Test Value = 0						
			Significance			95% Confidence Interval of the Difference	
	t	df	One-Sided p	Two-Sided p	Mean Difference	Lower	Upper
TP1wantedvhad	-.422	145	.337	.674	-.08904	-.5059	.3278

Table R.3: One-sample test on the exposure variable at time point 2

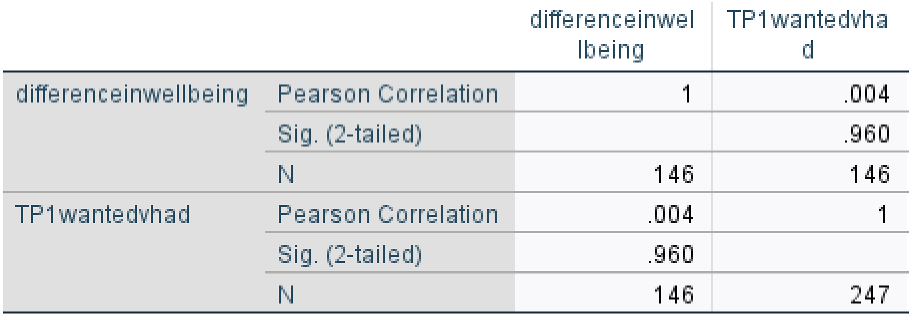


	Test Value = 0						
			Significance			95% Confidence Interval of the Difference	
	t	df	One-Sided p	Two-Sided p	Mean Difference	Lower	Upper
TP2wantedvhad	5.725	145	<.001	<.001	1.10274	.7220	1.4834

RQ3.2

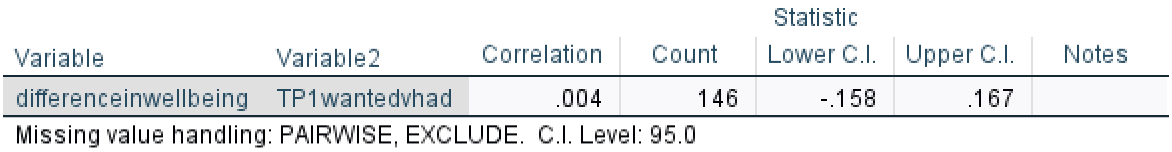
- H_0: There is no relationship between the difference between alone-time wanted and alone-time had at time point 1, and the change in wellbeing from time point 1 to time point 2
- H_1: There is a relationship between the difference between alone-time wanted and alone-time had at time point 1, and the change in wellbeing from time point 1 to time point 2

Table R.4: Pearson's correlation of the difference between time point 1 and time point 2 with the difference between alone-time wanted and alone-time had at time point 1



		differenceinwellbeing	TP1wantedvhad
differenceinwellbeing	Pearson Correlation	1	.004
	Sig. (2-tailed)		.960
	N	146	146
TP1wantedvhad	Pearson Correlation	.004	1
	Sig. (2-tailed)	.960	
	N	146	247

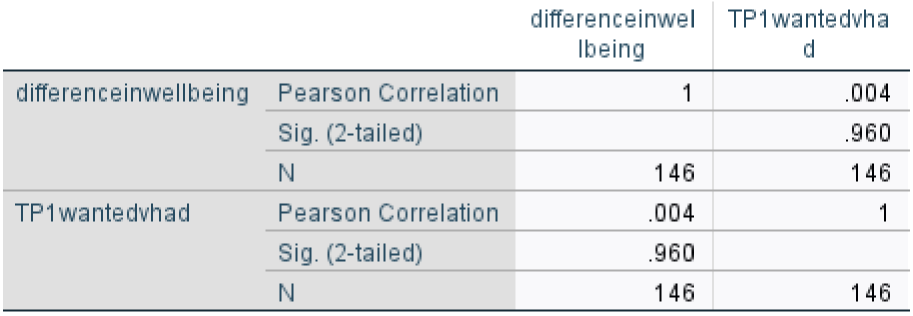
Table R.5: Correlation between the change in wellbeing at each time point and the difference between alone-time wanted and alone-time had at time point 1



		Statistic				
Variable	Variable2	Correlation	Count	Lower C.I.	Upper C.I.	Notes
differenceinwellbeing	TP1wantedvhad	.004	146	-.158	.167	

Missing value handling: PAIRWISE, EXCLUDE. C.I. Level: 95.0

Table R.6: Sensitivity test of Pearson's correlation of the difference between time point 1 and time point 2 with the difference between alone-time wanted and alone-time had at time point 1

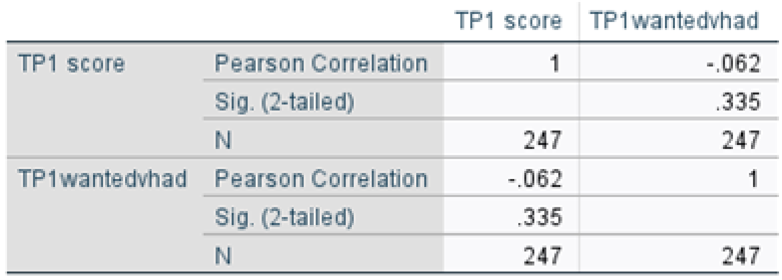


		differenceinwellbeing	TP1wantedvhad
differenceinwellbeing	Pearson Correlation	1	.004
	Sig. (2-tailed)		.960
	N	146	146
TP1wantedvhad	Pearson Correlation	.004	1
	Sig. (2-tailed)	.960	
	N	146	146

RQ3.3

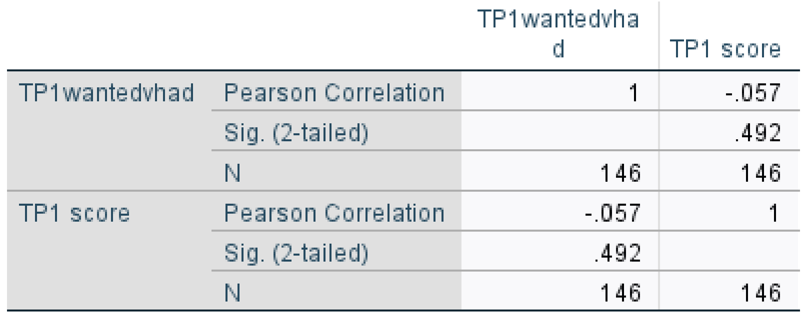
- H_0: There is no relationship between the difference between alone-time wanted and alone-time had at each time point, and wellbeing at the same time point
- H_1: There is a relationship between the difference between alone-time wanted and alone-time had at each time point, and wellbeing at the same time point

Table R.7: Pearson's correlation of the difference between alone-time wanted and alone-time had at time point 1, with wellbeing at time point



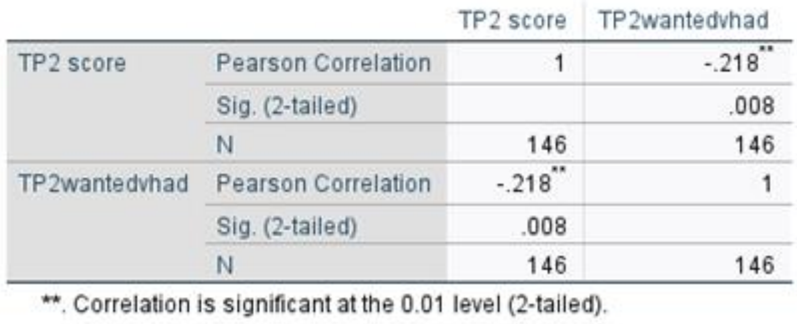
		TP1 score	TP1wantedvhad
TP1 score	Pearson Correlation	1	-.062
	Sig. (2-tailed)		.335
	N	247	247
TP1wantedvhad	Pearson Correlation	-.062	1
	Sig. (2-tailed)	.335	
	N	247	247

Table R.8: Sensitivity test of Pearson's correlation of the difference between alone-time wanted and alone-time had at time point 1, with wellbeing at time point



		TP1wantedvhad	TP1 score
TP1wantedvhad	Pearson Correlation	1	-.057
	Sig. (2-tailed)		.492
	N	146	146
TP1 score	Pearson Correlation	-.057	1
	Sig. (2-tailed)	.492	
	N	146	146

Table R.9: Pearson's correlation of the difference between alone-time wanted and alone-time had at time point 2, with wellbeing at time point 2



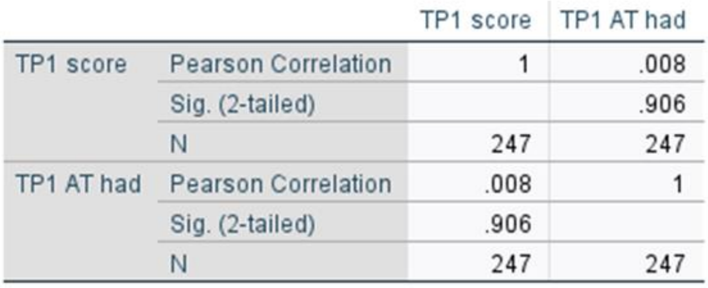
		TP2 score	TP2wantedvhad
TP2 score	Pearson Correlation	1	-.218**
	Sig. (2-tailed)		.008
	N	146	146
TP2wantedvhad	Pearson Correlation	-.218**	1
	Sig. (2-tailed)	.008	
	N	146	146

**. Correlation is significant at the 0.01 level (2-tailed).

RQ3.4

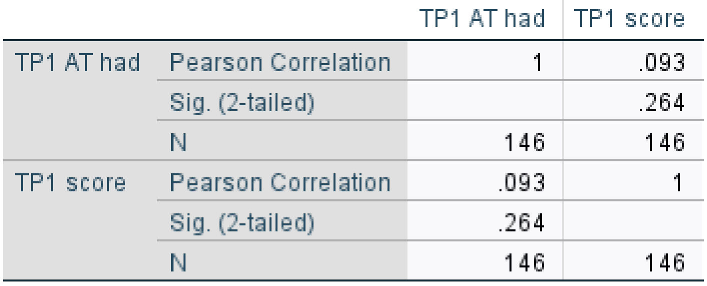
- H_0: There is no association between the number of alone-time hours had at each time point, and wellbeing at the same time point
- H_1: There is an association between the number of alone-time hours had at each time point, and wellbeing at the same time point

Table R.10: Pearson's correlation of alone-time had at time point 1 with wellbeing at time point 1



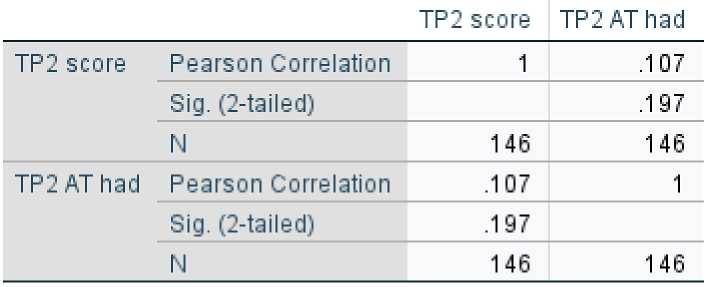
		TP1 score	TP1 AT had
TP1 score	Pearson Correlation	1	.008
	Sig. (2-tailed)		.906
	N	247	247
TP1 AT had	Pearson Correlation	.008	1
	Sig. (2-tailed)	.906	
	N	247	247

Table R.11: Sensitivity test of Pearson's correlation of alone-time had at time point 1 with wellbeing at time point 1



		TP1 AT had	TP1 score
TP1 AT had	Pearson Correlation	1	.093
	Sig. (2-tailed)		.264
	N	146	146
TP1 score	Pearson Correlation	.093	1
	Sig. (2-tailed)	.264	
	N	146	146

Table R.12: Pearson's correlation of alone-time had at time point 2 with wellbeing at time point 2

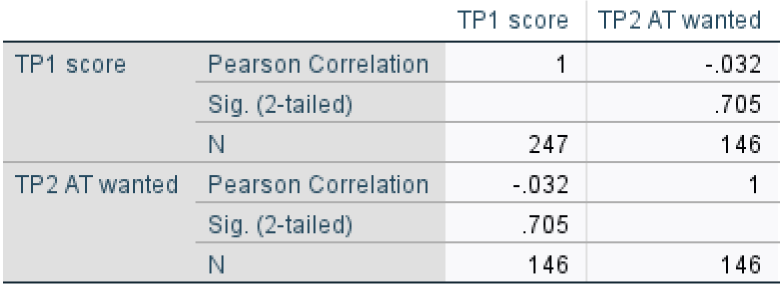


		TP2 score	TP2 AT had
TP2 score	Pearson Correlation	1	.107
	Sig. (2-tailed)		.197
	N	146	146
TP2 AT had	Pearson Correlation	.107	1
	Sig. (2-tailed)	.197	
	N	146	146

RQ3.5

- H_0: There is no association between wellbeing at time point 1 AND the number of alone-time hours wanted at time point 2
- H_1: There is an association between wellbeing at time point 1 AND the number of alone-time hours wanted at time point

Table R.13: Pearson's correlation to show relationship between wellbeing at time point 1 with alone-time wanted at time point 2



		TP1 score	TP2 AT wanted
TP1 score	Pearson Correlation	1	-.032
	Sig. (2-tailed)		.705
	N	247	146
TP2 AT wanted	Pearson Correlation	-.032	1
	Sig. (2-tailed)	.705	
	N	146	146

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