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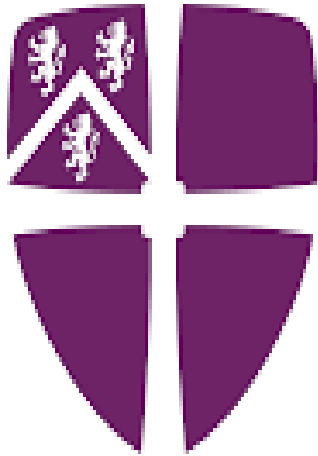
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# Durham University

**‘An examination of the perspectives of autistic adults about their engagement in  
physical activity’**

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**Durham University**

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**Department of Sport and Exercise Sciences**

**Durham University**

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## **Abstract**

Emerging research suggests that physical activity (PA) participation with autistic adults is low. Despite this fact, little is known about why their PA participation is low. The low

participation rates among autistic adults is problematic given that PA participation can confer numerous physical, mental, and social benefits. To date, autistic adults perspectives have been absent from PA research, and there is paucity of research examining how intrapersonal processes interconnect with interpersonal, environmental and policy-level processes to shape their PA participation. In this study, seventeen autistic adults participated in two online semi-structured interviews. Reflexive thematic analysis was used to organize the data and interpreted further by the social ecological model. The study findings highlight that sensory sensitivities, the personal trainer's style of coaching, and trust were important interconnected processes that shaped autistic adults PA participation. The study findings are significant because they illuminate that PA participation was not a behaviour solely influenced by intrapersonal processes such as motivation or self-concept. Rather, for the autistic adults in this study, sensory sensitivities, the personal trainer's style of coaching, and trust were interconnected to influence, hinder, and/or shape PA participation. This interconnected understanding of PA participation among autistic adults described in this study provides a valuable contribution to the field of autism research as it highlights the need to understand the multi-level processes associated with PA participation. The results of this work suggest that future research should focus on how the multi-level processes associated with PA among autistic adults interconnect to shape PA participation rather than focusing on how these processes function independently to shape PA participation.

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## **Chapter 1**

### **1.1. Introduction**

Physical inactivity has been associated with many challenges throughout life (van Sluijs et al., 2021; Bauman et al., 2012; King & King, 2010) in the general population. For example, physical inactivity has been identified as one of the leading causes of non-communicable diseases (Lee et al., 2012) and is considered the fourth leading risk factor for reported annual deaths (World Health Organisation, 2023). Equally, research exploring the mental health



implications of physical inactivity has also identified that physical inactivity is one of the multifactorial causes of suicide ideations (Jiang et al., 2020) and increasing the likelihood of experiencing anxiety disorders (McDowell et al., 2019; Schuch et al., 2019; Logan et al., 2018) and symptoms of depression (Codella & Chirico, 2023; Wanjau et al., 2023; Pearce et al., 2022). In addition, emerging research suggests that physical inactivity may increase the likelihood of experiencing feelings of loneliness (Pels & Kleinert, 2016) and social isolation (Robins et al., 2016). The impacts of physical inactivity are particularly concerning for autistic people as they may be more susceptible to experiencing the impacts of physical inactivity as they are less likely to participate in physical activity (PA) when compared to the general population (Healy et al., 2021; Vasudevan, 2021; Must et al., 2015; Memari et al., 2012).

Despite the fact that research consistently suggests that autistic people<sup>1</sup> are less likely to participate in PA when compared to the general population, PA participation has the potential to confer numerous physical, mental, and social benefits for autistic people (Jachyra et al., 2023; Blagrove et al., 2021; Colombo-Dougovito et al., 2021; Sowa & Meulenbroek, 2012; Hillier et al., 2011; García-Villamizar et al., 2010; Lockbaum & Crews, 2003; Elliot et al., 1994). Documented benefits of PA participation have been associated with improvements in aerobic capacity (Lockbaum & Crews, 2003), motor competencies (Sowa & Meulenbroek, 2012), quality of life (García-Villamizar et al., 2010), and mental well-being (Hillier et al., 2011). Participating in PA has also been associated with decreases in maladaptive and stereotypic behaviours (Elliot et al., 1994), stress (García-Villamizar et al., 2010), and anxiety (Hillier et al., 2011). Furthermore, emerging research suggests that PA participation can

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<sup>1</sup> Throughout this thesis, we adopt identity-first language (i.e., we describe participants as autistic people) to reflect that autism is a normal form of human variation and to respect the findings of Kenny and colleagues (2015) study. However, we also recognise that not all people agree with this type of language and that there is a diversity of perspectives regarding the most appropriate way of conceptualising and describing ASD. We recognise that the language used to describe ASD is important as it can influence peoples thoughts and perceptions of what ASD is and what autistic people are.

contribute to feelings of enjoyment (Blagrove et al., 2021; Colombo-Dougovito et al., 2020) and can serve as an outlet from daily life (Jachyra et al., 2023) among autistic adults. The fact that PA participation can serve as an outlet from daily life is particularly important for autistic adults as being neurodivergent in a neurotypical world can present unique challenges for autistic adults that can potentially negatively impact their quality of life (Finch et al., 2022).

Despite the manifold positive benefits of PA participation documented among autistic adults, research consistently suggests that autistic adults PA participation is low (Healy et al., 2021; Hillier et al., 2020; Benson et al., 2018; Hamm & Yun, 2017). To this end, emerging research from Canada suggests that only 17.6% of autistic adults currently meet the government's PA guidelines of at least 150 minutes of moderate-vigorous PA or 75 minutes of vigorous PA (Benson et al., 2018) and often self-report engaging in low levels of PA (Hamm & Yun, 2017). In the United States, lower levels of PA participation have also been observed among autistic adults (Hillier et al., 2020). In this vein, Hillier and colleagues (2020) found that autistic adults participate in less PA when compared to their age-related neurotypical peers. While these contributions are important in their own right, there is a salient need to work with autistic adults from the United Kingdom (UK) to understand their PA participation and experiences as their perspectives have been relatively absent from PA research. Further still, given that context and culture are one of the manifold determinants of PA behaviours (Seefeldt et al., 2002), there is a pressing need to work with autistic adults from the UK to understand their PA experiences as they are likely different from the documented experiences of autistic adults from the United States or Canada.

The low levels of PA participation observed among autistic adults is particularly concerning, as they may be more susceptible to experiencing the impacts of physical inactivity. In this vein, as emerging research suggests that autistic adults participate in less PA when compared to the general population (Healy et al., 2021; Hillier et al., 2020; Benson et al., 2018; Hamm

& Yun, 2017), they are at an increased risk of experiencing the impacts of physical inactivity. Given that autistic adults participate in low levels of PA, there is a need to work directly with autistic adults to better understand their PA participation and how to support them. Gathering first-hand perspectives from autistic adults is important because their perspectives have been largely absent from PA research. Conducting research in this area is important as it may allow us to augment our understanding of the processes that influence, hinder, and/or shape autistic adults PA participation.

To date, much of the research examining PA participation has been conducted with autistic children and adolescents (Piven & Rabins, 2011), proxy stakeholders (e.g., parental perspectives) (See for example Nichols et al., 2018), and/or young autistic adults (Waldron et al., 2022). From the research that has sought to examine PA participation among autistic adults have either relied on parental perspectives (Nichols et al., 2018), predominantly worked with young autistic adults (< 35 years) (Colombo-Dougovito et al., 2020; Kim et al., 2020), or worked with a relatively low sample of autistic adults that are 35 years of age or older outside of the UK (Waldron et al., 2022; Kim et al., 2020). As a result, there remains a current dearth of research solely working with autistic adults ( $\geq 35$  years) to provide an in-depth examination of the processes that influence, hinder, and/ or shape their PA participation. With research suggesting that PA behaviours, experiences, and participation can vary largely across different stages of the life course (Office for Health Improvement & Disparities, 2022; Hirvensalo & Lintunen, 2011; Zick et al., 2007), there is a need for more research to be conducted directly with autistic adults. Conducting research with autistic adults ( $\geq 35$  years) is important, as it may allow us to augment our understandings of the processes that influence, hinder, and/or shape their PA participation. Furthermore, gathering first-hand perspectives from autistic adults is important as it may allow us to develop a more in-depth understanding of how to design policies, programmes, and supports that are tailored to the diverse needs of autistic adults.

In addition to the dearth of research directly working with autistic adults, there is also a lack of research examining how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation. To date, the majority of the research suggests that the aforementioned processes operate in isolation to shape PA participation among autistic adults. In this vein, research examining PA participation among autistic adults has identified several intrapersonal, interpersonal, environmental, and policy-level processes that can shape their PA participation. To this end, intrapersonal processes such as perceived behavioural control have been identified as a process that can shape PA participation among autistic adults (Hillier et al., 2020). At the interpersonal level, positive social support (Colombo-Dougovito et al., 2020) and family advocacy (Buchanan et al., 2017) have also been found to influence autistic adults PA participation. Furthermore, emerging research has identified that environmental processes can also potentially influence PA participation. For example, Colombo- Dougovito and colleagues (2020) and Blagrove and colleagues (2021) found that autistic adults PA participation can be influenced when PA environments are congruent to their sensory sensitivities, needs, and preferences. In addition, policy-level processes such as accessibility to available programmes (Nichols et al., 2018) can also potentially influence PA participation. Although these contributions in their own right are important, we suggest that autistic adults PA is a complex behaviour that requires understanding processes at the intrapersonal, interpersonal, environmental, and policy-level. Therefore, given that a multiplicity of processes can potentially influence autistic adults PA participation, we suggest there is a pressing need to examine how the aforementioned processes interconnect to shape PA participation among autistic adults as this currently remains unknown.

With consideration to the knowledge gaps described above, the purpose of this qualitative study was threefold: (1) to examine the experiences of PA among autistic adults from the UK; (2) to examine how interpersonal processes shape autistic adults PA participation; and

(3) to examine how policy-level processes shape autistic adults PA participation. Consistent with the social ecological model (Bauman et al., 2012) that guided this study, we examined how the processes addressed by the research questions interconnected to shape PA participation among autistic adults.

## **Chapter 2**

### **2.1. Literature review**

#### **2.1.1. Introduction**

To contextualise the dissertation, I provide an overview of the literature and knowledge regarding PA participation among autistic adults. The literature review examines the current knowledge regarding PA participation for autistic people across the life course. The literature review examines PA participation for autistic people across the life course as much of the research to date has been conducted with autistic children and adolescents (Piven & Rabins, 2011). As a result of the plethora of research in this area with children and youth, I initially outline the literature as it pertains to autistic children and youth before outlining the current knowledge about PA with autistic adults. I do so to illustrate that there is a paucity of research working with autistic adults when compared to autistic children and adolescents. Examining PA participation across the life course can “potentially help in understanding PA

behaviours over the lifespan” (Hirvensalo & Lintunen, 2011, p. 1). The review of the literature also identifies theoretical and methodological knowledge gaps regarding PA participation among autistic adults. Substantively, the review of the literature highlights a paucity of research that has examined PA participation among autistic adults that are 35 years of age and older (henceforth >35). With much of the research to date examining PA participation from the perspectives of autistic children and adolescents (Piven & Rabins, 2011), proxy stakeholders (e.g., parental perspectives) (See for example Nichols et al., 2018), and/or young autistic adults (Waldron et al., 2022), there is a current dearth of research solely working with autistic adults that are 35 years of age and older to understand their PA participation. Gathering first-hand perspectives from autistic adults ( $\geq 35$  years) to understand their PA participation is important because their perspectives have been absent from PA research. Conducting research in this area is important as it may allow us to augment our understanding of the processes that influence, hinder, and/or shape autistic adults PA participation.

In addition to the dearth of research solely working with autistic adults ( $\geq 35$  years), there is also a lack of understanding about how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation (Cynthia et al., 2019). To date, the majority of the research suggests that the aforementioned processes operate in isolation to shape PA participation among autistic adults (See for example Hillier et al., 2020). In this vein, research examining PA participation among autistic adults has identified several intrapersonal, interpersonal, environmental, and policy-level processes that can shape their participation (Blagrave et al., 2021; Colombo-Dougovito et al., 2020; Hillier et al., 2020; Nichols et al., 2018; Buchanan et al., 2017). For example, intrapersonal processes such as perceived behavioural control have been identified as a process that can shape PA participation among autistic adults (Hillier et al., 2020). At the interpersonal level, positive social support (Colombo-Dougovito et al., 2020) and family

advocacy (Buchanan et al., 2017) have also been found to influence autistic adults PA participation. Furthermore, emerging research has identified that environmental processes can also potentially influence PA participation. For example, Colombo- Dougovito and colleagues (2020) and Blagrove and colleagues (2021) found that autistic adults PA participation can be influenced when PA environments are congruent to their sensory sensitivities, needs, and preferences. In addition, policy-level processes such as accessibility to available programmes (Nichols et al., 2018) can also potentially influence PA participation. Although these contributions are important, we suggest that autistic adults PA participation is a complex behaviour that requires understanding processes at the intrapersonal, interpersonal, environmental, and policy-levels. Therefore, in order to gain a more comprehensive understanding of PA participation among autistic adults, there is a need to examine how the aforementioned processes interconnect to influence, hinder, and/or shape PA participation.

From a theoretical perspective, the review of the literature highlights a paucity of research that has examined how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation.

Examining how these interconnections shape PA participation among autistic adults is important, as it may allow us to augment our understanding of the processes that interconnect to influence, hinder, and/or shape their engagement in PA. Although there is a body of research that has employed social ecological models to examine how these interconnections shape PA participation amongst the autistic population, much of the research to date has been conducted with autistic children (See for example Lee et al., 2022), autistic adolescents (See for example Gürkan & Koçak, 2021), and/or proxy stakeholders (e.g., parental perspectives of autistic adult children's PA participation) (Buchanan et al., 2017). Although these contributions have developed our understandings of PA participation for autistic people across the life course, it remains imperative to examine how the aforementioned processes

interconnect to shape autistic adults PA participation, as this currently remains unknown. Given the theoretical knowledge gap described above, we draw upon the social ecological model (Bauman et al., 2012) (See Chapter 3) to examine how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape PA participation among autistic adults.

### **2.1.2. Structure of literature review**

With consideration to the theoretical and methodological knowledge gaps described above, I begin the literature review by providing an overview of the bio-medical perspective of autism spectrum disorder (ASD). I begin the literature review by introducing the bio-medical perspective of ASD as it historically and currently remains the dominant perspective (Mac Carthaigh, 2019). In this process, I highlight how ASD is predominantly characterised and described from a bio-medical perspective while outlining some of the common co-occurring conditions that have been identified across the literature. Although the bio-medical conceptualisation of ASD remains the dominant viewpoint, it is important to recognise that there are alternative conceptualisations and perspectives of ASD (Pellicano & den Houting, 2021). Given that the bio-medical perspective is not the only way to describe ASD, I then outline the neurodiversity perspective of ASD to further contextualise how ASD is understood both in research and among autistic people. In this process, I then begin to introduce the disagreement between using identity-first language (IFL) and person-first language (PFL) to describe ASD to illuminate the varying perspectives between using IFL and PFL. I introduce the disagreement between using IFL and PFL to describe ASD, as it is important and has the potential to influence how others perceive and think about ASD and autistic people. I then highlight the language and terminology that will be used throughout the thesis. Following this, I examine the benefits of PA for autistic children and adolescents before highlighting the benefits of PA among autistic adults. I then initially describe the facilitators to PA for autistic children and adolescents before moving to describe the



facilitators to PA among autistic adults. After examining the benefits and facilitators to PA, I draw upon research that suggests that autistic people (i.e., autistic children, adolescents, and adults) are less likely to participate in PA throughout the life course. Given the lower levels of PA observed among autistic people, I then turn to examine the barriers to PA for autistic children and adolescents before describing the barriers to PA for autistic adults. After examining the barriers to PA for autistic adults, I then summarise and conclude the literature review before moving on to the theoretical framework (See Chapter 3) section of the thesis.

In the field of autism research, much of the research to date has been conducted with autistic children (See for example Healy et al., 2013) and autistic adolescents (See for example Jachyra et al., 2020). Due to the abundance of research in the field of autism research focusing on children and youth, I initially outline the literature as it pertains to autistic children and youth before outlining the current knowledge about PA with autistic adults. I do so to illustrate that there is a paucity of research working with autistic adults when compared to autistic children and adolescents, which served as an impetus for this study. Now that I have now outlined and described how the literature review is structured, I now turn to discuss and outline the bio-medical perspective of ASD.

## **2.2. What is autism spectrum disorder?**

### **2.2.1. Bio-medical perspective**

From a bio-medical perspective, ASD is conceptualised as a neurodevelopmental disorder characterised by deficits in social communication and the presence of restricted interests and repetitive behaviours (Hodges et al., 2020). In the bio-medical sciences, ASD is a medical condition characterised by impairments in social communications, social interactions, and restricted or repetitive behaviours (American Psychiatric Association, 2013). Although the aetiology of ASD remains unknown (Cambridge Center for Behavioural Studies, 2022), evidence suggests that ASD is influenced by a combination of genetic and environmental factors (Hodges et al., 2020; Emberti Gialloreti et al., 2019; Karimi et al., 2017; LaSalle et

al., 2013; Hertz-Picciotto et al., 2006). For example, evidence suggests that an advanced maternal and paternal age at conception ( $\geq 35$  years) (Hertz-Picciotto et al., 2006), epigenetics (LaSalle et al., 2013), and postnatal complications (e.g., low birth weight and size) (Karimi et al., 2017) can influence the development of ASD. In the UK, approximately 1 in every 100 people have been diagnosed with ASD (National Autistic Society, 2022). Prevalence estimates suggest that boys are approximately three times more likely to be diagnosed with ASD when compared to girls (Loomes et al., 2017). However, it is important to recognise that miss-diagnosis or under-diagnosis of ASD is more common among girls (See Stark, 2019; Gould & Ashton-Smith, 2011). The notion that more girls are miss-diagnosed or under-diagnosed with ASD when compared to boys is significant, as it may leave girls unable to access appropriate support systems that they should be entitled to access throughout their lives. Furthermore, going under-diagnosed or miss-diagnosed may present girls with unique challenges that may increase their likelihood of experiencing adverse mental health (Hull et al., 2020). Autism is recognised as a “spectrum” disorder as there is significant variation in the number and severity of ASD symptoms that autistic people display (Georgiades et al., 2013). Due to this heterogeneity in the number and severity of ASD symptoms, varying impacts on social communication, social interactions, and restricted or repetitive behaviours have been observed. ASD symptoms are usually identified by clinicians during early childhood (Blenner et al., 2011) and contribute to functional impairments in social reciprocity, communication, and repetitive restricted patterns of behaviour or interests (American Psychiatric Association, 2013). Although ASD symptoms are usually identified during early childhood, it is important to recognise that ASD screening and diagnosis can occur later in life (Centre for Disease Control and Prevention, 2023). To this end, a large UK-based study found that twenty adults per 100,000 patients were diagnosed with ASD during adulthood (Russell et al., 2021). Even though ASD diagnosis in adulthood is becoming more common, it is important to note that the same study by Russell and colleagues (2021) found

that most ASD diagnosis predominantly occur during childhood. In addition to the impairments in social reciprocity, communication, and repetitive patterns of behaviour or interests, a number of co-occurring conditions have been widely documented in the literature (Rosen et al., 2018; Besag, 2017; South & Rodgers, 2017; Sokolova et al., 2017; Sokhadze et al., 2015; Schieve et al., 2015; Russell & Pavelka, 2013; Miano & Ferri, 2010). To this end, research suggests that common co-occurring conditions can include (but are not limited to): attention deficit hyperactivity disorder (Sokolova et al., 2017); insomnia (Miano & Ferri, 2010); learning disabilities (Schieve et al., 2015); epilepsy (Besag, 2017); dyslexia (Russell & Pavelka, 2013); dyspraxia (Sokhadze et al., 2015); anxiety (South & Rodgers, 2017); and depression (Rosen et al., 2018), among others. The co-occurring conditions commonly associated with ASD are concerning because they have been associated with many potential challenges throughout life (Doygan & Mazurek, 2019; Dunn et al., 2018; Lever & Geurts, 2016). For example, the presence of ASD and intellectual disability has been associated with poorer health status and has been found to limit the day-to-day activities of autistic people (Dunn et al., 2018). Furthermore, emerging research suggests that the co-occurrence of ASD and attention deficit hyperactivity disorder can have a negative impact on autistic people's health-related quality of life (Doygan & Mazurek, 2019). In addition to the impacts on health-related quality of life, the co-occurrence of ASD and mood disorders can have a detrimental impact on autistic people's employment and education opportunities and may make it more difficult to build interpersonal relationships with others (Doygan & Mazurek, 2019). The presence of co-occurring conditions can not only make autistic people's lives potentially more difficult but can also limit their opportunities to participate in PA by having a harmful impact on their health and well-being. The academic and political landscape has been dominated by the bio-medical perspective of ASD since Kanner's (1943) description of ASD. However, it is important to recognise that there are alternative conceptualisations and perspectives that emerged to challenge the pathological conceptualisations of ASD (See Singer, 1998). In what

follows below, I outline the alternative perspective of ASD, which is often referred to as the neurodiversity perspective.

### **2.2.2. Neurodiversity perspective**

The neurodiversity perspective of autism can be understood as a movement that argues that ASD should be viewed as a “normal human difference that should be tolerated and respected in the same way as other human differences” (Jaarsma & Welin, 2012, p. 4). Instead of viewing ASD as a bio-medical pathology that negatively impairs those with ASD, individuals affirming a neurodiversity perspective conceptualise ASD as a lifelong neurodevelopmental difference that influences how a person interacts and communicates with others and experiences the world (Pellicano et al., 2022). Informed by the social model of disability (Oliver et al., 2012), neurodiversity perspectives view autistic people as disabled not by their impairments but by the failure of their environment to account for their needs (Den Houting, 2018). As Psychology Today (2023) puts it, “proponents of neurodiversity believe that society should work to eliminate stigma, create accommodations, and fully accept people with autism as capable of contributing to society”. As such, the neurodiversity movement aims to empower neurodiverse individuals to take ownership of their own personal narratives by promoting their experiences and views above those of physicians and scientists (Sonuga-Barke & Thapar, 2021). It is important to recognise that since Singer (1988) first coined the term neurodiversity, the neurodiversity perspective of ASD has increasingly gained traction among both the autistic and autism communities, as it is believed to promote more positive narratives about autistic people (Pellicano & den Houting, 2021). However, like many other social justice movements, the neurodiversity perspective of ASD has been highly criticised (Den Houting, 2018), and not all autistic people agree with the narratives that the neurodiversity movement hopes to promote. Similar to the disagreement between the bio-medical and neurodiversity conceptualisations and perspectives of autism, the language and terminology used to describe ASD are also political issues (Vivanti, 2019; Kenny et al., 2015;

Nicolaidis, 2012). In this vein, there is substantial disagreement regarding the terminology and language used to describe ASD (Vivanti, 2019; Kenny et al., 2015; Nicolaidis, 2012). In the UK, some people prefer to adopt IFL (i.e., describing someone as an autistic person), while others prefer to adopt PFL (i.e., describing someone as a person with autism) (Kenny et al., 2015). Given this disagreement in perspectives, I now move to discuss and outline the implications of adopting IFL to describe ASD. Following this, I then discuss and outline the implications of adopting PFL to describe ASD. In this process, I highlight how our decision to adopt IFL was informed. As will become apparent below, I will adopt IFL in this thesis to reflect that autism is a natural form of human variation (Chapman, 2019) and to respect the preferences stated by the autistic adults in Kenny and colleagues (2015) UK-based study. Now that I have outlined and described the neurodiversity perspective of ASD, I now turn to outline and describe the implications of using IFL to describe ASD.

### **2.2.3. Identity-first language**

Similar to the disagreement between the bio-medical and neurodiversity perspectives of ASD outlined above, the language and terminology used to describe ASD are also political issues (Vivanti, 2019; Kenny et al., 2015; Nicolaidis, 2012). In this vein, there are multiple perspectives among researchers, medical professionals, and autism advocates regarding the terminology and language used to describe ASD. These perspectives generally fall into two categories: IFL or PFL (Vivanti, 2019; Nicolaidis, 2012). The use of IFL (i.e., describing someone as an autistic person) conforms to the social model of disability and suggests that autistic people are not disabled by their impairments but by the failure of their environment to account for their needs (Den Houting, 2018). From this perspective, autistic people are viewed as people who experience, interact with, and see the world differently, rather than autism being considered a negative phenomenon categorised by bio-medical pathology (Raising Children Network, 2022). Although there is substantial disagreement around the most appropriate way of describing autism in the UK (See Kenny et al., 2015), those who

adopt IFL often advocate that they aim to eradicate negative narratives around autism, as IFL promotes the view that autistic people are individuals who are not solely defined by their autism (Buijsman et al., 2022). The disagreement surrounding the most appropriate way of describing autism further extends to other countries such as the Netherlands (See Buijsman et al., 2022) and Australia (See Bury et al., 2022). Although autistic adults in the UK generally prefer to adopt IFL, it is important to recognise that there is a diversity of perspectives from other countries. For example, a study in the Netherlands found that autistic adults prefer to adopt PFL rather than adopting IFL (Buijsman et al., 2022). These findings are significant as they contradict Kenny and colleagues (2015) findings and reinforce the substantial disagreement surrounding the most appropriate way of describing autism. Now that I have outlined and described the implications of using IFL to describe ASD, I now turn to outline and describe the implications of using PFL to describe ASD.

#### **2.2.4. Person-first language**

In contrast to IFL, PFL (i.e., describing someone as a person with autism) conforms to the medical model of disability (Haslett & Smith, 2020). From this viewpoint, a “person with autism” is perceived as someone “with an impairment in a body system or function that is inherently pathological” (American Psychological Association, 2023). As a result of these impairments, under the medical conceptualisation of disability intervention research seeks to treat or rehabilitate a “person with autism” (Dirth & Branscombe, 2017). Advocates of PFL often argue that describing someone as a “person with autism” has the potential to reduce discrimination and stereotypes as it draws attention to the person rather than their condition (Bury et al., 2020). Despite this fact, those who oppose PFL suggest that using unconventional language to describe autism may reinforce stigma rather than reduce it (Taboas et al., 2022). Given that there is no universally accepted way of describing ASD, I recognise that the language and terminology used to describe autism is important and can have significant implications. Language has the potential to influence thought and perception

(Hunt & Agnoli, 1991) and can “empower and support autistic people while also changing the attitudes of the broader community” (Monk et al., 2022, p. 971). Recognising the impact of language use, I now turn to outline and discuss the language and terminology that will be used throughout the thesis.

### **2.2.5. Language and terminology**

Throughout this thesis, I will use IFL when referring to individuals with an ASD diagnosis as opposed to PFL. Kenny and colleagues (2015) UK cohort study found that autistic adults prefer to be known as “autistic people” rather than “people with autism”. As previously mentioned, it is important to consider the language used to describe autism, as it has the potential to influence thought and perception (Hunt & Agnoli, 1991). Furthermore, it can “empower and support autistic people while also changing the attitudes of the broader community” (Monk et al., 2022, p. 971). Therefore, I use IFL given the preferences stated by autistic adults in Kenny and colleagues (2015) study, as I am also conducting research with autistic adults within the context of the UK. Now that I have established the language and terminology that will be used throughout this thesis, I now turn to discuss the benefits of PA participation among autistic children and adolescents.

## **2.3. Physical activity participation**

### **2.3.1. Physical activity benefits: autistic children and adolescents**

Participating in PA has been identified as a vital element of healthy living for all as it can contribute to the prevention and management of non-communicable diseases (NCB) and can improve mental well-being (World Health Organisation, 1995). In this vein, PA participation has been shown to reduce the risk of developing and managing NCB such as obesity (Hong et al., 2014); atherosclerotic cardiovascular disease (Thompson et al., 2003), and strokes (Gallanagh et al., 2011). Furthermore, participating in PA has also been associated with improvements in managing anxiety (Kandola et al., 2018), quality of life (Gill et al., 2013), along with decreases in symptoms of depression (Currier et al., 2020) and suicidal thoughts (Vancampfort et al., 2018). In addition to these mental benefits, engagement in PA can also

foster improvements in enjoyment and pleasure experiences (Phoenix & Orr, 2014), sociality (Di Barolomeo & Papa, 2017) and identity formations (Allender et al., 2006). Conceptualised as any bodily movement produced by skeletal muscles that requires energy expenditure (World Health Organisation, 1995), PA is considered an important and cost-effective enabler to support public health and a vehicle to achieve the United Nations 2030 Sustainable Development Goals due to its ability to attenuate non-communicable diseases (Dai & Menhas, 2020). For autistic people, research consistently suggests that PA participation has the potential to confer a range of physical, mental, and social benefits across the life course (Rafiei Milajerdi et al., 2021; Pan et al., 2016; Fox, 2015; Sowa & Meulensbroek, 2012; Johnson, 2009). For example, PA participation has been associated with improvements in aerobic capacity (Johnson, 2009), muscular strength (Johnson, 2009), and motor competencies (Rafiei Milajerdi et al., 2021) among autistic children and adolescents. Participating in PA has also been associated with improvements in quality of life (Jimeno, 2019), quality of sleep (Nguyen et al., 2021), social communication skills (Fox, 2015), cognition (Pan et al., 2016), and mental well-being (Sowa & Meulensbroek, 2012), along with decreases in self-stimulating behaviours (Lang et al., 2010) and self-injurious behaviours (Sorensen & Zarett, 2014). In addition to these physical and mental health benefits, emerging research suggests that PA participation can provide a sense of structure, routine, and predictability (Gregor et al., 2018) and can be a potential opportunity to make friends (Gregor et al., 2018) among autistic children and adolescents. Although much of the research examining the impacts of PA participation has been conducted with autistic children and adolescents (Hillier et al., 2020; Kunzi, 2015), research suggests that the benefits of PA documented among autistic children and adolescents are similar to the observed benefits of PA for autistic adults. To this end, as has been observed among autistic children and adolescents PA participation has also been associated with many physical, mental, and social benefits among autistic adults (See



for examples, Lockbaum & Crews, 2003; Hillier et al., 2011; Jachyra et al., 2023). It is to this discussion that I now turn.

### **2.3.2. Physical activity benefits: autistic adults**

Among autistic adults, PA participation has been associated with improvements in aerobic capacity (Lockbaum & Crews, 2003), motor competencies (Sowa & Meulenbroek, 2012), quality of life (García-Villamizar et al., 2010), and mental well-being (Hillier et al., 2011). Participating in PA has also been associated with decreases in maladaptive and stereotypic behaviours (Elliot et al., 1994), stress (García-Villamizar et al., 2010; Hillier et al., 2011), and anxiety (Hillier et al., 2011). Furthermore, emerging research suggests that PA participation can contribute to feelings of enjoyment (Blagrove et al., 2021; Colombo-Dougovito et al., 2020) and can serve as an outlet from daily life (Jachyra et al., 2023) among autistic adults. Despite the many benefits that have been attributable to PA participation for autistic people across different stages of the life course, research suggests that the rates of PA participation among autistic people is low (See Blagrove et al., 2021; Memari et al., 2015; Jachyra et al., 2020; Hillier et al., 2011), particularly during adulthood (Garcia-Pastor et al., 2018). To better understand why autistic people are less likely to participate in PA, I now turn to examine the facilitators and barriers to PA participation for autistic people across the life course. As will become apparent below, there are many facilitators reported across the literature, particularly for autistic children and adolescents, but there is a lack of documented research with autistic adults.

## **2.4. Physical activity facilitators**

### **2.4.1. Physical activity facilitators: autistic children and adolescents**

To date, a large majority of the research examining the impacts of PA has been conducted with autistic children and adolescents (Hillier et al., 2020; Kunzi, 2015; Piven & Rabins, 2011). Therefore, there is an abundance of research that has sought to examine the facilitators to PA participation among autistic children and adolescents (Boucher et al., 2022; Jachyra et al., 2020; Arnell et al., 2017; Obrusnikova & Miccinello, 2012; Obrusnikova & Cavalier,

2010). For autistic children and adolescents, research suggests that parental support (Obrusnikova & Cavalier, 2010), encouragement from friends and peers (Obrusnikova & Cavalier, 2010), and being rewarded or praised (Obrusnikova & Miccienllo, 2012) can facilitate PA participation. In addition, emerging research suggests that other key facilitators include (but are not limited to): a freedom of choice to choose the type of PA (Arnell et al., 2017); staff that are adequately trained to account for the diverse needs, interests, and abilities of autistic children and adolescents (Boucher et al., 2022); and family identity (i.e., family valuing PA) (Jachyra et al., 2020). Autism research in the UK has rarely included research with autistic adults (Pellicano et al., 2014). Although there are likely many reasons for why research has rarely included autistic adults from the UK, this may partially be explained by autism long being considered a disorder that manifests in early development (Blenner et al., 2011). Therefore, researchers may have prioritised focusing on working with autistic children and adolescents in order to better understand how to support autistic people early in life. Although research that has sought to examine the facilitators of PA among autistic adults is sparse (Colombo-Dougovito et al., 2020), emerging research suggests that some of the facilitators to PA participation documented among autistic children and adolescents extends to autistic adults (Blagrove et al., 2021; Colombo-Dougovito et al., 2020; Kim et al., 2020; Nichols et al., 2018; Buchanan et al., 2017). However, as will become apparent below, it is important to note that there are some additional facilitators to PA documented among autistic adults. To further contextualise the dissertation, I now turn to discuss the facilitators to PA for autistic adults.

#### **2.4.2. Physical activity facilitators: autistic adults**

Although there is a dearth of research that has sought to examine the facilitators of PA among autistic adults (Colombo-Dougovito et al., 2020), evidence suggests that some of the facilitators described across the literature among autistic children and adolescents' extend to autistic adults (Blagrove et al., 2021; Colombo-Dougovito et al., 2020; Kim et al., 2020;

Nichols et al., 2018; Buchanan et al., 2017). To this end, emerging research suggests that positive social support (Colombo-Dougovito et al., 2020), family advocacy (i.e., family encouraging and valuing PA behaviours) (Buchanan et al., 2017), and an environment that is congruent to the sensory sensitivities, needs, and preferences of autistic adults can facilitate PA participation (Colombo-Dougovito et al., 2020; Blagrove et al., 2021). In addition, emerging research suggests that other key facilitators to PA participation are adequate financial resources (Nichols et al., 2018) and access to available programmes (Nichols et al., 2018). Furthermore, research conducted by Kim and colleagues (2020) found that predictable and persistent interfaces throughout an online mobile game designed to increase PA were key facilitators to PA participation among autistic adults. Despite the many positive associations of PA and facilitators described throughout the literature for autistic people across the life course, the importance of PA is underscored by evidence showing that autistic people tend to be less physically active when compared to the general population (Healy et al., 2021; Vasudevan, 2021; Must et al., 2015; Memari et al., 2012). Lower levels of PA participation have been observed throughout the life course, from childhood through to adulthood (Healy et al., 2021; Must et al., 2015; Memari et al., 2012). I now turn to outline physical inactivity among autistic children and adolescents to further contextualise the dissertation.

## **2.5. Physical inactivity**

### **2.5.1. Physical inactivity: autistic children and adolescents**

Although PA participation for autistic young people has the potential to confer many benefits, research consistently suggests that autistic young people are less physically active when compared to their peers (Vasudevan, 2021), particularly during adolescence (Obrusnikova & Cavalier, 2010). Resultantly, research has sought to examine autistic children's and adolescents PA patterns and behaviours to better understand their PA participation (Ketcheson et al., 2017; Must et al., 2015; Memari et al., 2012). In this vein, research suggests that autistic children are less likely to participate in school and community-based PA (Must et al., 2015) and are less likely to meet the World Health Organisation's recommended

guidelines of 60 minutes of moderate to vigorous daily PA (Ketcheson et al., 2017) when compared to their age-related peers. In addition, lower levels of PA participation have also been observed during adolescence, where the biggest drop-off in PA participation observed between autistic young people and their neurotypical peers occurs (Memari et al., 2012). The lower levels of PA observed among autistic children and adolescents are particularly concerning as they may potentially miss out on the effective pleasures of movement (Jachyra et al., 2020; Jachyra & Gibson, 2016) and potentially experience adverse physical and mental health effects given their lack of participation in PA. Given that research suggests that the PA patterns of behaviours documented for autistic children and adolescents extend to autistic adults (Healy et al., 2021; Hillier et al., 2020; Benson et al., 2018; Hamm & Yun, 2017), I now turn to examine physical inactivity among autistic adults. Examining physical inactivity among autistic adults is of utmost importance as it will not only further contextualise the dissertation but will also highlight the need for this study.

### **2.5.2. Physical inactivity: autistic adults**

Despite PA participation being associated with many benefits for autistic adults, research consistently suggests that autistic adults are less likely to be physically active (Healy et al., 2021; Hillier et al., 2020; Benson et al., 2018; Hamm & Yun, 2017) and tend to be less active when compared to autistic children and adolescents (Garcia-Pastor et al., 2018). In this vein, emerging research suggests that only 17.6% of autistic adults currently meet the government's PA guidelines of at least 150 minutes of moderate-vigorous PA or 75 minutes of vigorous PA (Benson et al., 2018) and often self-report engaging in low levels of PA (Hamm & Yun, 2017). Furthermore, the notion that autistic adults tend to engage in less PA is supported by Hiller and colleagues (2020) findings. In a study of autistic adults in the United States, Hillier and colleagues (2020) found that autistic adults participate in less PA, hold less favourable attitudes towards PA, report having low perceived behavioural control, and experience many barriers to participate in PA when compared to their age-related

neurotypical peers. With consideration to research that suggests that autistic people across the life course often experience many barriers to participate in PA, I now turn to examine the barriers to PA participation among autistic children and adolescents before moving to describe the barriers to PA among autistic adults.

## **2.6. Barriers to physical activity participation**

### **2.6.1. Barriers to physical activity participation: autistic children and adolescents**

Given that autistic people across the life course tend to engage in low levels of PA, research has sought to examine why they are predominantly inactive. Various barriers to PA participation have been identified (Jachyra et al., 2020; Duquette et al., 2016; Memari et al., 2015; Must et al., 2015; Memari et al., 2012; Healy et al., 2013; Obrusnikova & Cavalier, 2010). In this vein, common barriers to PA participation include difficulties in social communication and limited motor abilities (e.g., poor co-ordination and balance) (Must et al., 2015), a lack of motivation (Obrusnikova & Cavalier, 2010), family time constraints (Must et al., 2015), a lack of financial resources (Memari et al., 2015), a lack of time (Memari et al., 2015), and sensory sensitivities (Duquette et al., 2016) among autistic children and adolescents. In addition to these individual barriers to PA participation, emerging research suggests that environments that are too competitive or intense (Duquette et al., 2016), a lack of available programmes (Memari et al., 2012), exclusionary environments (Healy et al., 2013), and frequent experiences of bullying and exclusion (Jachyra et al., 2020; Healy et al., 2013) can deter autistic children and adolescents from participating in PA. Emerging research suggests that some of the barriers documented among autistic children and adolescents also extend to autistic adults (See for examples Healy et al., 2021; Hillier et al., 2020; Nichols et al., 2018). I now turn to describe the barriers to PA participation among autistic adults below.

### **2.6.2. Barriers to physical activity participation: autistic adults**

Research consistently suggests that autistic adults are predominantly inactive (Healy et al., 2021; Hillier et al., 2020; Benson et al., 2018; Hamm & Yun, 2017) and tend to be less active

when compared to autistic children and adolescents (Garcia-Pastor et al., 2018). Given that autistic adults tend to be less physically active, emerging research has sought to examine why they tend to be physically inactive (Healy et al., 2021; Hillier et al., 2020; Nichols et al., 2018). In this vein, a lack of transportation (Healy et al., 2021), difficulties in social situations (Nichols et al., 2018), and behavioural outbursts (Nichols et al., 2018) can act as barriers to PA participation among autistic adults. Furthermore, sensory sensitivities (Nichols et al., 2018), a lack of perceived behavioural control (Hillier et al., 2020), and perceiving PA as mundane (Healy et al., 2021) have been found to act as barriers to PA participation among autistic adults.

## **2.8. Summary and conclusion**

In this chapter, I highlighted how ASD is characterised and described from a bio-medical perspective. I then outlined some of the common co-occurring conditions that have been identified across the literature. Following this, I then highlighted how ASD is characterised and described from a neurodiversity perspective and highlighted the disagreement between IFL and PFL. I then outlined how the decision to utilise IFL throughout the thesis was influenced by the literature findings. Following this, I examined the benefits of PA among autistic children and adolescents before turning to describe the benefits of PA among autistic adults. Given that, across the field of autism, much of the research to date has been conducted with autistic children (See for example Healy et al., 2013) and autistic adolescents (See for example Jachyra et al., 2020), I throughout the literature review outlined the autistic children's and adolescents' literature findings before moving to outline the autistic adult's literature findings. The research described above illustrates that there remains a paucity of research working with autistic adults when compared to autistic children and adolescents. This gap served as an impetus for this study. In the sections that followed, I examined the benefits of PA for autistic people across the life course. I then moved on to examine the facilitators to PA before highlighting that autistic children, adolescents, and adults tend to be

less physically active. Recognising that autistic people tend to be less physically active, I then examined the barriers to PA described across the literature. With the literature often only describing the facilitators and barriers to PA participation among the autistic population (Papadopoulous et al., 2020; Nichols et al., 2018; Must et al., 2015; Obrusnikova & Calvier, 2010), I conclude the literature review by suggesting there is a need to move beyond describing the facilitators and barriers to PA among autistic adults ( $\geq 35$  years). Despite their important contributions, I suggest there is a need to examine how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to influence, hinder, and/or shape PA participation among autistic adults, as this currently remains unknown. Given the need to examine how these interconnections shape autistic adults PA participation, the social ecological model (Bauman et al., 2012) will be the adopted theoretical framework to foreground my analysis. The social ecological model will be the adopted theoretical framework as it is considered “useful because it emphasises the dynamic and interactive relationships between individuals and their physical and social environment (Hock & Ahmedani, 2012). From a social ecological perspective, development (in this case, PA behaviours) is viewed as a complex process by which individual development is not solely determined by the individual but rather an interplay between the individual and multi-levels of the environment (Guy-Evans, 2023). In the chapter that follows, I turn to describe the theoretical framework that will be adopted in this study to examine how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to influence, hinder, and/or shape autistic adults PA participation.

## **Chapter 3**

### **3. Theoretical Framework**

#### **3.1. An introduction to social ecological models**

In the context of understanding PA behaviours, social ecological models are based on the notion that multiple processes ranging from the individual to the environment and policy can directly, indirectly, and/or interconnect to influence PA behaviours (Rhodes et al., 2019). The social-ecological perspective as we know it today is based upon the seminal work of Urie Bronfenbrenner (Spence & Lee, 2003; Rhodes et al., 2019; Buchanan et al., 2017). Urie Bronfenbrenner was a Russian-born American psychologist who was once revered as one of the world's most distinguished scientists for establishing ecological systems theory (Brendtro, 2006). Originally proposed as a theory of child development in 1979 (See Bronfenbrenner, 1979), ecological systems theory asserts that there is a reciprocal



relationship between an individual and multiple levels of the immediate and surrounding environment that can potentially influence a child's development (Guy-Evans, 2023). According to Bronfenbrenner's (1979) nomenclature of ecological systems theory, five nested ecological contexts interact with and influence each other to shape all aspects of a child's life. Bronfenbrenner conceptualised these ecological contexts as: the microsystem, the mesosystem, the ecosystem, the macrosystem, and the chronosystem. These five ecological contexts were arranged in order of how much impact they have on development (Guy-Evans, 2023). Although Bronfenbrenner's perspective has been modified to examine health behaviours, the core tenets of social ecological models make the framework appropriate for examining PA behaviours, as there is a wealth of evidence demonstrating that PA behaviours have multiple levels of influence (Rhodes et al., 2019). In this chapter, I begin by outlining and describing the social ecological model which guided the study. In this process, I provide justifications for why, in this study, it was appropriate to employ Bauman and colleagues (2012) iteration of the social ecological model to examine autistic adults PA participation. Following this, I then describe the research fields that have applied social ecological models to examine PA behaviours. I do so to demonstrate the model's utility in examining the multiple interconnected processes that can influence, hinder, and/or shape PA participation. I then move to explain how, in this study, it was appropriate to employ the social ecological model to examine PA participation among autistic adults. I conclude the chapter by briefly outlining how the theoretical and conceptual underpinnings of Bauman and colleagues (2012) social ecological model guided the analysis of PA participation among autistic adults.

### **3.2. The social ecological model**

Since the late 20th century, social ecological models have been widely applied to understand PA behaviours (van Kasterern et al., 2020). Although there are various types of social ecological models (Ding, 2020), they are all predicated on the notion that PA behaviours are influenced by multiple interconnected processes (Spence and Lee, 2003). The social

ecological model by Bauman and colleagues (2012) posits that PA behaviours can be influenced by intrapersonal processes (e.g., gender), interpersonal processes (e.g., social support), environmental processes (e.g., PA facilities), and policy-level processes (e.g., a lack of trained staff) (Arkesteyn et al., 2023). According to Bauman and colleagues (2012), this type of social ecological model is particularly useful when examining PA behaviours, as it comprehensively examines PA behaviours given that it highlights that processes at all levels can influence PA behaviours. Furthermore, as Spence and Lee (2003) point out, when examining the processes that influence PA behaviours, ecological models are more effective than traditional individualistic models as they recognise that PA behaviours have multiple influences. In this study, it was important to employ Bauman and colleagues (2012) iteration of the social ecological model to examine autistic adults PA participation for three main reasons. Firstly, Bauman and colleagues (2012) iteration of the social ecological model was employed in the current study because the core tenets of the model aligned with the research questions the study aimed to address. To this end, this study sought to examine how intrapersonal processes interconnected with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation. Therefore, it was appropriate to use Bauman and colleagues (2012) to guide the analysis of autistic adults PA participation, as this iteration of the social ecological model considers how the aforementioned processes can influence PA behaviours. Secondly, the social ecological model was employed in this study, as it was important to adopt a theoretical framework that would allow us to consider how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation. This was important because how these processes interconnect to shape autistic adults PA participation is a significant gap in the literature. In this vein, to date, emerging research suggests that intrapersonal (Hillier et al., 2020), interpersonal (Colombo-Dougovito et al., 2020; Buchanan et al., 2017), environmental (Blagrove et al., 2021; Colombo-Dougovito et al., 2020), and policy-level processes (Nichols

et al., 2018) operate in isolation to influence, hinder, and/or shape autistic adults PA participation. Although these contributions are important, we suggest that examining PA participation among autistic adults is a complex behaviour that requires understanding how the aforementioned processes interconnect to shape autistic adults PA participation. Therefore, it was appropriate to adopt the social ecological model to achieve this. Third and finally, Bauman and colleagues (2012) iteration of the social ecological model was strategically selected to facilitate the examination of the processes that shape autistic adults PA participation. Unlike other social ecological models (e.g., McLeroy et al., 1998), Bauman and colleagues (2012) iteration of the social ecological model narrowly focuses on how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape PA behaviours. Therefore, given that the core tenets of the model aligned with the research questions we sought to address, Bauman's and colleagues (2012) iteration was employed in the current study. Now that I have outlined and described the social ecological model which guided this study, I now turn to outline the research fields that have applied social ecological models to examine PA behaviours. As previously mentioned, I introduce the research fields that have applied social ecological models to illustrate the social ecological model's utility in examining PA behaviours.

### **3.3. The social ecological model and its application to examine autistic adults PA participation**

Social ecological models have been widely used to examine PA participation among various populations (Ding, 2020). For example, social ecological models have been used to examine PA participation among African women (Fleury & Lee, 2006) and dropout in women's sports (Craike et al., 2009). Furthermore, in Canada, Langille & Rodgers (2010) applied the social ecological model to examine the various social ecological processes that influence school based PA interventions. Similarly, a systematic review by Hu and colleagues (2021) applied the social ecological model to explore the processes that influence PA in school-aged children and adolescents. Importantly, other studies in the field of autism research have

employed social ecological models to examine the processes that shape PA participation among autistic children and adolescents (Arkesteyn et al., 2023; Gürkan & Koçak, 2021; Obrusnikova & Miccinello, 2012; Obrusnikova & Cavalier, 2011). The studies conducted with autistic children and adolescents are important to recognise as they demonstrate that social ecological models are an appropriate framework to examine PA participation among the autistic population. Now that I have outlined and described the research fields that have applied social ecological models to examine PA behaviours, I now turn to conclude the chapter.

### **3.4. Conclusion**

In this chapter, I have outlined and described the social ecological model which guided this study. In this process, I then justified why it was appropriate to employ Bauman and colleagues (2012) iteration of the social ecological model to examine autistic adults PA participation. Following this, I then described the various research fields that have applied social ecological models to examine PA behaviours. I then moved to explain how it was appropriate to employ the social ecological model to examine PA participation among autistic adults. In alignment with the theoretical and conceptual underpinnings of Bauman and colleagues (2012) social ecological model, the analyses focused on examining how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape PA participation among autistic adults. In the following chapter, I now turn to describe and outline the methods employed in the current study.

## **Chapter 4**

### **4. Methodology**

#### **4.1. Introduction**

In the field of autism research, qualitative investigations are less common than quantitative investigations (Bölte, 2014). Bölte's (2014) publication came at a time when there were calls from the UK's autistic and autism communities to change the trajectory of research that tended to prioritise funding towards research focused on the "basic sciences" (e.g., genetics) rather than funding projects that sought to embed the autistic voice (See Pellicano & Stears, 2011) and involve autistic adults directly (Pellicano et al., 2014). The calls from the UK's autistic and autism communities (See Pellicano et al., 2014 for extended discussion) is important to recognise as the number of qualitative investigations in the field of autism have since increased (Parenteau et al., 2023). Despite the increase in the number of qualitative investigations in the field of autism, much of the qualitative research focused on examining PA participation have been conducted with autistic children (See for example Healy et al., 2013), autistic adolescents (See for example Jachyra et al., 2020), young adults (<35 years) (See for example Colombo-Dougovito et al., 2020), and/or proxy stakeholders (e.g., parental perspectives) (See for example Nichols et al., 2018).

Given that much of the qualitative research examining PA participation to date has not widely included autistic adults, there is a clear need to work directly with autistic adults to embed the autistic adults voice within research. It is of paramount importance to work directly with autistic adults (>35 years) to better understand their PA participation, as research suggests that PA behaviours, experiences, and participation can vary largely across different stages of the life course (Office for Health Improvement & Disparities, 2022; Hirvensalo & Lintunen, 2011; Zick et al., 2007). Furthermore, conducting research with autistic adults is important as it holds the potential to develop novel insights regarding the processes that influence, hinder, and/or shape their engagement in PA that have not been previously described in research. Similarly, working with autistic adults also holds the potential to develop a more intricate and nuanced understanding of how to design programmes, interventions, supports, and policies that are congruent to their diverse needs, interests, and abilities.

Given that working directly with autistic adults holds the potential to develop novel insights regarding the processes that influence, hinder, and/or shape their engagement in PA, I now move to describe the methods employed in the current study. As will become apparent below, the methods carried out in the current study were designed with the utmost due diligence, and all ethical considerations and implications were extensively considered. Across the field of autism, there have been several publications that have brought attention to the fact that the autistic community (i.e., autistic people) often distrust those conducting autism research (Woods & Waltz, 2019; Pellicano & Stears, 2011). Given this distrust, we employed methodologies that would allow us to work directly with autistic adults whilst embedding the autistic voice (See Pellicano and Stears, 2011) within our research in the hope of alleviating the distrust from the autistic community.

To begin the process of describing the methods employed in the current study, I outline the ontological and epistemological assumptions that underpinned our worldview about reality. Following this, I then describe and outline the study design before describing and outlining

participant sampling and recruitment. In the section that follows the outline of participant sampling and recruitment, I then turn to provide a description of the participants. I then turn to describe the sampling strategy employed in the current study before providing justifications for including two semi-structured interviews (SSI) in the current study. I then turn to describe and outline both SSI used in the current study. In the section that follows, I then turn to outline some of the advantages and disadvantages of conducting online interviews. To conclude the chapter, I describe and outline how the interview data were analysed. I now turn to outline the ontological and epistemological assumptions that underpinned our worldview about reality.

#### **4.2. Ontological and epistemological assumptions**

The ontological and epistemological assumptions of qualitative research are fundamentally different from the ontological and epistemological assumptions that inform quantitative research (Smith & McGannon, 2017). In contrast to quantitative researchers that generally assume an objective reality exists and can be discovered independent from the researcher (Slevitch, 2011), qualitative researchers often assume that multiple realities exist and that knowledge is constructed and subjective (Smith & McGannon, 2017). Given these divergent viewpoints about reality, it is important for qualitative researchers to explicitly state the ontological and epistemological assumptions that underpins their worldview about reality, as it allows the reader to understand the philosophical presuppositions that inform their work (Sparkes & Smith, 2013). Therefore, this qualitative study assumed a relativist ontology (i.e., multiple realities exist and are influenced by our minds; we all have our own perceptions of reality; see Sparkes & Smith, 2013, p. 11) and a subjectivist epistemology (i.e., knowledge is acquired through our social interactions; see Sparkes & Smith, 2013, p. 13). Given our ontological and epistemological assumptions about reality, this study employed an interpretive qualitative study design (see Nickerson, 2023) that was underpinned by the social ecological model (see Chapter 3 for an extended discussion). By taking an interpretive

qualitative approach, we aimed to examine how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape PA participation among autistic adults. In this study, it was important to employ a qualitative study that included two online SSI as it provided a platform to embed the autistic voice within our research (See Pellicano & Stears, 2011) whilst capturing the perceptions, experiences, and opinions (See Louise Barriball & While, 1994) of autistic adults about the processes that influence, hinder, and/or shape their PA participation. Now that I have established the ontological and epistemological assumptions that underpinned our worldview about reality, I now turn to outline the study design employed in the current study.

### **4.3. Study design**

This study employed a qualitative study design (Maxwell, 2009). Although there is no universal definition of what qualitative research is (Sparkes & Smith, 2013, p. 6), qualitative research can be conceptualised as “a form of social inquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live” (Sparkes & Smith, p. 14). According to Mays and Pope (1995), the aim of qualitative research is to explore, understand, and interpret social phenomena within their natural setting. As Tenny and colleagues (2017) put it, researchers who conduct qualitative research sought to answer the “whys” and “hows” by exploring participants, experiences, perceptions, and behaviours. In the field of autism research, conducting qualitative research is valuable as it can improve our understandings of autism and can lead to a deeper understanding of the processes that influence autistic people’s lives and experiences (See Bölte, 2014). In the context of this study, it was important to conduct qualitative research with autistic adults to explore their PA participation, as currently little is known in this research area. Furthermore, given that this research was exploratory in nature (Elliot & Timulak, 2015) and aimed to generate a more holistic understanding of autistic adults PA participation, it was important to conduct qualitative research that included interviews in order to increase the depth and richness of the



data to achieve the research aims and objectives (DiCicco-Bloom & Crabtree, 2006). Now that I have outlined and described the study design, I now turn to outline participant sampling and recruitment.

#### **4.3.1. Sampling and recruitment**

In this study, autistic adults were recruited from the UK through advertising on social media and engaging with gatekeepers from various autism support groups and charities. Autistic adults were invited to participate if they:

(a) had a clinical diagnosis or self-diagnosed with either: Autism, Pathological Demand avoidance, Aspergers syndrome, Autistic disorder, or Pervasive Developmental Disorder; (b) were at least 35 years old; (c) lived in the UK; (d) were able to understand verbal and written English language; and (e) were able to provide informed consent.

Each prospective participant was initially contacted through e-mail and requested to confirm their diagnosis status, age, and where they lived to ensure eligibility. To assess verbal and written proficiency, prospective participants were initially asked during the introductory discussion to describe some of their personal interests and hobbies and were also asked to describe their understanding of the current study. Prospective participants who met the inclusion criteria and were interested and able to engage in extended discussions about their PA participation were invited to participate in the study. At this time, informed consent was sought from participants. Throughout the introductory interview, questions such as “What kinds of things do you like to do?” or “Do you have any activities or interests that you really like?” were used. These rapport interview building questions were guided by the experience of the supervisory team who have extensively conducted interviews with autistic people as it relates to health and well-being (See Jachyra et al., 2019; Jachyra et al., 2018). To facilitate building trust and rapport, prospective participants were then provided with the opportunity to openly ask questions about the researcher at the end of the interview. Generally, prospective participants were interested in establishing the primary author’s interests and

motivations for conducting research with autistic adults. This study received ethical approval from Durham University’s Sport and Exercise Sciences Ethics Committee, and the associated risk assessment was approved by the Department of Sport and Exercise Sciences Health and Safety Committee. Now that I have established participant sampling and recruitment, I now turn to provide a description of the participants.

#### 4.4. Participant description

In this study, 17 autistic adults (See Table 1 for participants demographic information) participated in two online SSI. Autistic adults were recruited from the UK through advertising on social media and engaging with gatekeepers from various autism support groups and charities. All autism support groups and charities received an email with a detailed report of the project’s aims, requirements, and potential benefits of participating (See Appendix A). All autism support groups and charities also received an email with a recruitment flyer (See Appendix B) to facilitate participant recruitment.

Name	Age	Gender	Diagnosis Status	Diagnosis Age	Co-occurring Conditions	Diagnosis Route	Employment Status	Region of UK	D A	MD PA
Barbra	48	F	Diagnosed ASD	44	Arthritis Anxiety	ND	Full time employment	Yorkshire and the Humber region	0	0
Sam	46	M	Diagnosed ASD	46	ADHD	Public	Full time employment	North East region	4	30
Haley	50	F	Diagnosed ASD	44	Arthritis Dyspraxia	Public	Full time employment	North East region	7	60-180
Georgia	52	F	Diagnosed ASD	48	Dyspraxia Dyslexic SD ADHD	Private	Full time student	Yorkshire and the Humber region	0	0
Jude	48	F	Diagnosed ASD	48	SD ADHD Dyspraxia Anxiety	Public	Full time employment	North East region	4	20
Sarah	46	F	Diagnosed ASD	45	Anxiety Panic Disorder Depression Eating disorder	Private	Full time employment	South West region	5	180

Harry	50	M	Diagnosed ASD	40	SD: ADHD Hypertension Anxiety Acid Reflux	Public	Full time employment	London region	5	30-60
Ellen	53	F	SD ASD	35	Hypermobility Ehlers Danlos syndrome	ND	Unemployed	London region	0	0
Mary	45	F	Diagnosed ASD	41	SD: Dyspraxia Hypermobility	Private	Self-employed	East of England region	3 / 4	60
Anna	36	F	Diagnosed ASD	8	Dyslexia Dyspraxia Sensory Processing Disorder OCD	Public	Full time employment	Yorkshire and the Humber region	7	20-40
Cassie	47	F	Diagnosed ASD	43	SD: ADHD Dyslexia Ehlers Danlos Syndrome Eating Disorder Chronic Migraines	Public	Unemployed	West Midlands region	0	0
Brandon	52	M	Diagnosed ASD	48	SD: Pathological Demand Avoidance, Anxiety Depression Hypermobility	Public	Full time employment	Eastern Scotland region	7	120
Colin	59	M	Diagnosed ASD	54	ADHD SD: OCD Bipolar disorder	Public	Unemployed	North East region	7	120
Kathleen	49	F	Diagnosed ASD	46	ADHD Endometriosis Depression Anxiety	Public	Part time employment	East Midlands region	7	45
Lindsey	53	F	Diagnosed ASD	52	Fibromyalgia Depression Anxiety Anorexia PTSD Arthritis	Public	Part time employment	West Midlands region	7	30-60

Valerie	51	F	SD ASD	N/A	Hypermobility Dysautonomia	N/A	Unemployed	South East region	0	0
Stacey	54	F	SD ASD	N/A	Hypermobility	N/A	Self-employed part time	South East region	7	60

Key: DA= Days active MDPA= minutes of daily PA N/A= Not applicable F= Female M= Male SD= Self diagnosed ND= Not disclosed

*Table 1: Participants Demographic Information*

As displayed in Table 1, most participants in this study identified as female, with a noticeable gap in participants who identified as male and diverse identities. Even though the high participation rates of autistic females in this study is somewhat enigmatic considering their historical under-representation in autism research (D’Mello et al., 2022), there are two plausible reasons for why many participants in this study were females. First, the high participation rates of autistic females observed in this study could potentially represent the growing awareness of the manifestation of autism in girls and women (Moseley et al., 2020). To this end, it is possible that the dispellment of outdated and inaccurate stereotypes (e.g., ASD being rarely diagnosed among females; Lai et al., 2015) influenced the autistic females motivations to participate in study by eradicating the prevailing stigma commonly associated with identifying as an autistic female (see Turnock et al., 2022). Second and finally, it is first important to recognise that the high participation rates of autistic females observed in this study could be coincidental as our recruitment efforts were not targeted towards solely recruiting autistic females. However, it is plausible that the high participation rates of autistic females observed in this study could also have been supported by the growing influence of the ideologies pushed by many autism advocacy support groups (e.g., Autism Alliance, 2024). To this end, it is possible that one of the core tenets promoted by many autism advocacy support groups and communities (e.g., a need for greater representation and involvement of autistic people in research) encouraged the autistic female's participation in the study.

#### **4.5. Sampling strategy**

In this study, participants were recruited through purposive sampling (Campbell et al., 2020). Purposive sampling is a type of non-probability sampling technique where researchers purposively select participants that possess certain characteristics that allows them to achieve their research aims and objectives (Campbell et al., 2020). Even though purposive sampling strategies can be susceptible to research biases (Acharya et al., 2012), a homogenous purposive sampling strategy was employed in the current study as we aimed to work with a hard-to-reach population (i.e., autistic people) that shared similar demographics (e.g., >35 years old). Furthermore, to enhance the rigour and reliability of the study, a purposive sampling strategy was also employed in the current study due to its ability to better select participants that aligned with the aims and objectives of this study (Campbell et al., 2020). In this study, it was appropriate to employ a purposive sampling strategy as we were interested in recruiting autistic adults from the UK who were at least 35 years old. Now that I have outlined and described the sampling strategy employed in the current study, I now move to provide justifications for including two SSI in the current study.

#### **4.6. Semi-structured interviews**

In qualitative research, interviews are the most common data collection method (Minhat, 2015; Hofisi et al., 2014). There are various types of interviews, and each one is different in terms of its structure and the number of participants in each interview (See Smith & Sparkes, 2016, p. 104). These generally fall into four categories: individual structured interviews; individual SSI; individual unstructured interviews; and focus groups (Smith & Sparkes, 2016, p. 104). In contrast to a structured interview that predominantly asks closed-ended questions (Smith & Sparkes, 2016, p. 104), SSI often use a combination of closed and open-ended questions (Adams, 2015). To guide conversations during SSI, a preplanned interview guide is commonly used (Kallio et al., 2016). In exploratory research, SSI are often used as a tool to develop a more in-depth understanding of the perceptions and opinions of participants (Jachyra et al., 2015) about a particular social phenomenon (Louise Barribell & White, 1994).

Although there is no “gold standard” for how long SSI should last, evidence suggests that SSI should not exceed 60 minutes to minimise both participant and researcher fatigue (Adams, 2015). Furthermore, SSI are considered a well-suited data collection method in research fields where little is known about the topic of interest (Adam, 2010).

In exploratory research, interviews are considered a powerful data collection method (Jain, 2021). In this study, it was important to select SSI as the data collection method for five main reasons. Firstly, SSI were employed in the current study, as currently little is known about autistic adults PA participation and experiences. Secondly, given that SSI are considered well suited in exploratory research (See Louise Barriball & While, 1994), it was important to employ SSI as our research questions were exploratory in nature. Thirdly, SSI were selected as a data collection method as it provided a platform for us to embed the autistic voice within our research (See Pellicano & Stears, 2011). Fourthly, given that rapport building with autistic people can be difficult in a single interview (See Jachyra 2020, p. 53), two SSI were included in the current study as a means to facilitate rapport building between both the researcher and participants. Additionally, two SSI were included in this study as a vehicle to alleviate the distrust among the autistic community (Woods & Waltz, 2019; Pellicano & Stears, 2011). In this vein, we included two SSI, as it was important to provide the participants with multiple opportunities to meet and learn more about the researcher to alleviate the distrust from the autistic community. Fifth and finally, SSI were employed in the current study as they provided the researcher with an opportunity to probe additional information and ask follow-up questions related to the research questions in order to generate a deeper understanding of PA participation among autistic adults. Furthermore, SSI were selected for their flexibility (Horton et al., 2004) to explore novel directions as they arose during the interviews. Now that I have provided justifications for including two SSI in the current study, I now turn to describe and outline both interviews used in the current study.

#### **4.7. Interview one**

Following recruitment, participants were invited to attend either two online or two in-person SSI. Despite being provided with the opportunity to attend in person, all 17 autistic adults in this study attended both interviews online. All interviews with participants were conducted on either Microsoft Teams or Zoom. Given that some people may be less familiar with using online platforms than others (See Lobe et al., 2022), participants who decided to conduct the interviews on Microsoft Teams were provided with the opportunity to receive a handout (See Appendix C), which used images alongside text briefly explaining how to access Microsoft Teams. The first interviews lasted between 15-38 minutes. All interviews were audio-taped using Otter transcription (See Otter, 2023) and then manually transcribed verbatim. During the first interview, conversations were guided by an SSI guide (See Appendix D), which was designed to elicit discussions about the study requirements and the participants personal interests. To begin the interview, the primary researcher ensured that participants met the eligibility criteria. Over the course of the first interview, questions such as “What kinds of things do you like to do?” and “Do you have any activities or interests that you really like?” were used to facilitate discussions about the participants personal interests. During and after the first interview, field notes were written to facilitate conversations in the second interview. To ensure informed consent was provided, participants were then required to electronically sign a consent form (See Appendix E for consent form template) before the commencement of the first interview. Following receiving informed consent from participants, a second interview was then scheduled. Now that I have outlined the first interview, I now turn to outline and describe the second interview included in this study.

#### **4.8. Interview two**

The second interview was conducted after the first interview with participants, and the interviews lasted between 21-82 minutes. All interviews were audio-taped using Otter transcription (See Otter, 2023) and then manually transcribed verbatim. During the second interview, conversations were guided by an SSI guide (See Appendix F), which was designed

to elicit discussions about the participants engagement in PA. The second interview commenced by asking participants why they engaged in PA to unearth their understandings of the physical, social, and mental benefits of PA participation. Over the course of the second interview, questions such as “Is there anything that you believe prevents you from engaging in physical activity?” and “Do you believe that the physical activity programmes offered to you meet your needs?” were further used to elicit discussion about the processes that influenced, hindered, and/or shaped PA participation among autistic adults. Generally, throughout the second interview, conversations with the participants were researcher-directed. However, in some instances (e.g., Mary), participants directed conversations during the interview. By using two SSI in this study, it allowed us to gain a comprehensive understanding of the processes that influenced, hindered, and/or shaped PA participation among autistic adults whilst building rapport and trust that more than likely would not have been achieved in a single interview. Now that I have described and outlined the second interview, I now turn to describe some of the opportunities and challenges that arose from utilising online interviews as a data collection method.

#### **4.9. Online Interviews: Advantages and Disadvantages**

As Fielding and colleagues (2017) allude to, since the advent of the internet and the introduction of various digital communication platforms, there has been a significant increase in the number of online research projects. Online interviews, a widely employed research method in social scientific research (Hooley et al., 2012), provided two main benefits in our study. First, online interviews were used in this study due to their ability to reach geographically dispersed participants (Sedwick & Spiers, 2009). To this end, online interviews were leveraged as a data collection method given that we sought to recruit autistic adults from across the UK. It was critical to include online interviews as it would have been difficult to capture a diverse sample of participants from across the UK if participants were required to attend the interviews in-person due to the associated costs of commuting to



Durham University. Second and finally, online interviews were included as we sought to establish a sense of safety with participants (Woods & Waltz, 2019) given a history of distrust with institutions experienced by the autistic community (Jachyra et al., 2024; Jachyra, 2020). To this end, as autistic people report experiencing many challenges during interviews (Finn et al., 2023), we provided participants with the autonomy to participate online, which allowed them to participate in an environment most familiar to them. This was critical not only to alleviate any anxiety or stress they may have experienced throughout the duration of the study, but also was leveraged in the hope that participants would be more willing to share more in-depth their PA experiences.

Despite some of the advantages of online interviews succinctly described above, conducting online interviews in this study presented three main challenges. First, one of the most salient challenges of conducting the interviews online pertained to interpreting the non-verbal forms of communication when working with participants. To this end, unlike in-person interviews that affords the researcher ample opportunities to analyse all forms of verbal and non-verbal communication (Seitz, 2015), interpreting the body language and behaviours of participants throughout the duration of the online interviews was particularly challenging due to the online nature of the study. This was because all the participants we worked with positioned their cameras in a way that only allowed the primary author to see the upper extremities of participants. Although our online approach afforded us to pay attention too and interpret the tone of voice and facial expressions of participants when sharing their experiences, it is important to acknowledge that the online nature of the study curtailed our ability to assess other forms of non-verbal cues (e.g., self-stimulatory behaviours such as hand flapping commonly reported among the autistic population; Lilley, 2018). This was particularly problematic because not being able to interpret other forms of non-verbal communication could have led the primary author to misunderstand or misinterpret the autistic adults emotional state when participating in the interviews. Second, another notable challenge of

conducting the interviews online related to the concept of interview shocks (Prior & Lachover, 2023). In this vein, while there are various forms of interview shocks (see Prior & Lachover, 2023), the emotional-cognitive shocks associated with conducting online interviews was difficult for the primary researcher especially when participants shared traumatic life experiences. While numerous mitigation strategies were implemented to safeguard participants, the primary author experienced vicarious trauma (Smith et al., 2021) when participants shared distressing life events (such as bullying or sexual abuse). These difficulties was exacerbated by the online format as it created a sense of emotional distance that made it challenging for the researcher to fully understand and process the traumatic content. Third and finally, building rapport with participants during the online interviews proved to be difficult. To this end, although two interviews were included in this project with the intention of fostering and facilitating rapport with participants, the presence of a laptop screen created a barrier that may have curtailed the development of trust and connection between the researcher and participants which would have otherwise been absent during an in-person interview. It is critical to acknowledge that the physical barrier created by the laptop screen could not only affected the depth and richness of the data collected but also could have made participants less forthcoming during the online interviews due to the lack of physical presence that is present in a traditional in-person interview. Now that I have outlined some of the advantages and disadvantages of conducting online interviews, I now turn to describe how the interview data were analysed.

#### **4.10. Data analysis**

All interviews (n = 34) were transcribed verbatim upon completion, and participants were assigned pseudonyms to conceal and protect their identities. The interview data were scrupulously analysed using reflexive thematic analysis (See Braun & Clarke, 2020; Braun & Clarke, 2019), and then the social ecological model was used to further interpret the data. According to Kiger and Varpio (2020), reflexive thematic analysis is a type of data analysis

method that is well-suited to understanding the perceptions, opinions, and behaviours of participants across a data set. Therefore, it was appropriate to select reflexive thematic analysis in this study as we sought to understand the perceptions, opinions, and behaviours of autistic adults regarding their PA participation. In this study, analysis was led by the primary author (who was a master's student at Durham University). Despite lacking prior experience of conducting in-depth interviews with the autistic community, the primary author was well-positioned to conduct the interviews with participants due to his previous experience of conducting in-depth interviews with combat sport athletes in his local community exploring their experiences of adverse mental health. To further increase the analytical rigour of the study (Wright Stein, 2021), the primary author was supported by his primary (Dr. Patrick Jachyra) and secondary (Professor Martin Roderick) supervisors with expertise in qualitative research, neurodevelopmental disability, autism, physical activity, mental health, and bioethics. These multidisciplinary approaches in turn allowed to take the data in new and different directions throughout the analysis (Jachyra et al., 2015).

To begin the analysis process, data familiarisation was initiated by the primary author transcribing all interview transcripts before reading and re-reading all interview transcripts (Braun & Clarke, 2006, p. 87). To conclude phase one of the analysis process, all interview transcripts were then manually annotated with initial ideas to help formulate and aid the formal coding process in phase two of the analysis. After formulating the initial ideas in phase one, phase two of the analysis process commenced with the primary author manually generating initial codes throughout the data set (Braun & Clarke, 2006, p. 89). While generating initial codes, highlighters were used to indicate potential patterns of meaning across segments of data. Phase three of the analysis process was then initiated by the primary author manually grouping codes into candidate themes and compiling information pertinent to each candidate theme (Braun & Clarke, 2006, pp. 89-90). To assist in grouping the codes into candidate themes, a manual visual representation (i.e., mind maps) of the data was

developed. The candidate themes represented key processes that influenced, hindered, and/or shaped PA participation among autistic adults. To initiate phase four of the analysis process, the candidate themes were then further reviewed and refined to ensure they related to the coded extracts and to the complete data set (Braun & Clarke, 2006, p. 91). Phase five was then initiated by the primary author, who then clearly defined and named the themes (Braun & Clarke, 2006, pp. 92-93), and then theory was used to further interpret the data using the social ecological model. The thematic analysis, in turn, helped organise the structure of the analysis and guided the results. After clearly defining and naming the themes, phase six of the analysis process was then initiated by the primary researcher producing the report (Braun & Clarke, 2006, p. 93). The analysis was considered complete when the three main themes were established.

## **Chapter 5**

### **5.1. Results**

Three themes emerged from the analysis of the processes that influenced PA participation among autistic adults. Findings suggest that sensory sensitivities, trust, and the personal trainer's style of coaching were important processes that shaped PA participation among autistic adults. Each theme represents processes that both enhanced and hindered autistic adults PA experiences. Consistent with the heterogeneous nature of ASD, the autistic adults in this study engaged in a wide array of PA behaviours in adulthood. In this vein, some participants were currently physically inactive, some were physically active but did not currently meet the UK PA guidelines, and some were highly active. Generally, the autistic adults in this study emphasised the mental benefits of PA when compared to the physical benefits of PA. In addition to the varying levels of PA engagement, many participants generally preferred to engage in individual forms of PA (e.g., walking, swimming and running) rather than group-based PA (e.g., team sports such as football or rugby).

Conceptually, when sharing their experiences of PA many of the autistic adults we worked

with focused on experiences of structured forms of PA (e.g., sports and exercise) rather than less structured forms of PA (e.g., gardening or completing household chores). All participants we worked with appeared to be hyperlexic and needed little to no support when participating in both interviews. Although emerging research suggests that a large majority of autistic adults from the UK are unemployed (Davies et al., 2024; Department for Work and Pensions, 2024; Office for National Statistics, 2021), many of the autistic adults we worked with were not only in full time employment but also appeared to be of a relatively high socio-economic status given they could afford and engaged in PA under the supervision of a personal trainer.

To begin the results section, I initially introduce and present each theme independently to examine how the theme shaped PA participation among autistic adults before moving to examine how the initial theme operated interdependently with the next theme to shape PA participation among autistic adults. To conclude the chapter, I reiterate the need to examine how different processes operate interdependently to shape PA participation among autistic adults. As will become apparent below, for the autistic adults in this study, PA participation was not merely determined by processes that operated in isolation that have been described previously in the literature but rather by processes that operated interdependently. To protect the identities of the participants, pseudonyms will be used throughout the chapter. I now turn to examine PA participation among autistic adults.

## **5.2. Sensory sensitivities**

### **5.2.1. Auditory sensory sensitivities**

Sensory sensitivities were ubiquitously described across many participants accounts. For many participants, sensory sensitivities were frequently experienced in community-based assets (CBA) and often hindered their PA experience and participation. In analysing the autistic adults accounts, it became apparent that the environment in CBA (such as gyms and leisure facilities) were not congruent to their various sensory needs and preferences. These experiences in turn resulted in a lack of engagement in community-based PA for many of the

autistic adults in this study. Across the data, there were many accounts that highlighted tacitly that sensory sensitivities were often characterised by feelings of trepidation, aversion, apathy, and overwhelm towards engaging in community-based PA (i.e., gyms and swimming pools). For some autistic adults, the experiences of sensory processing differences played a significant role in their experiences of burnout outside and within the sport and PA context. Although the autistic adults in this study drew upon various experiences where visual, tactile, and olfactory sensory sensitivities limited their PA participation, it was clear that auditory sensory sensitivities were particularly highlighted as a challenge when participating in PA in CBA. In recollecting their experiences, many autistic adults voiced that the dynamics of the environment in CBA posed auditory challenges when participating in community-based PA. The insights described below are significant because they demonstrate that intrapersonal processes (such as motivation) interconnected with environmental processes of the socioecological model to shape the autistic adults PA participation. To this end, Harry's account demonstrates that his lack of interest in participating in community-based PA derived from trepidation towards being unable to "filter out" the sound. For some participants, feelings of trepidation coincided with an aversion towards participating in community-based PA. Importantly, for the autistic adults in this study, their lack of interest towards participating in community-based PA derived from the lack of congruence between community-based spaces and their auditory sensory sensitivities. As Kathleen reflected, her aversion towards participating in community-based PA was associated with her inability to "control the noise". This previous negative experience of auditory sensory sensitivities limited Kathleen's PA participation because it made operating community-based spaces arduous. Auditory sensory sensitivities were not only associated with feelings of trepidation and aversion towards participating in community-based PA, but some participants also expressed feeling overwhelmed. To this end, some autistic adults in this study described that they felt auditory stimuli were entrenched within community-based PA environments. This

entrenchment of auditory modalities in community-based PA environments made their PA experiences arduous because they experienced physical and mental anguish. Narratives of feeling overwhelmed by auditory sensory sensitivities emerged from some participants' accounts of participating in community-based PA. For other participants, the challenges associated with community-based PA environments were exacerbated by the presence of multiple auditory stimuli. In this vein, Jude described feeling overwhelmed only when there were multiple auditory stimuli present. As Jude explained, "I can cope with the music and I can cope with the MTV unless you've got two different things on at the same time". This insight is critical as it demonstrates that the presence of multiple auditory stimuli in community-based PA environments served as a significant barrier to her PA participation. Similarly, Haley's narrative highlights how multiple auditory stimuli in community-based spaces can be overwhelming. To this end, Haley shared that "the 50 different noises" that are present in community-based spaces limited her opportunities to participate in community-based PA. The common occurrence of multiple auditory stimuli further instilled Haley's distrust towards participating in community-based PA environments. Haley's distrust towards participating in community-based environments is hardly surprising given that the environments in CBA were not congruent to her auditory sensory needs. For some participants, experiences of auditory sensory sensitivities in community-based PA environments were not only welcomed with distrust but resulted in complete avoidance of community-based PA. For instance, Valerie expressed that "the noise" in community-based PA environments underpinned her avoidance of community-based PA. Valerie's narrative is important because it demonstrates that auditory sensory sensitivities in community-based PA served as a barrier to her PA participation. An avoidance of community-based PA environments due to auditory sensory sensitivities was further reflected in Lindsey's account. Highlighting the impact of auditory sensory sensitivities, Lindsey noted:

“One of the worst things for me is the clanging sounds... the clanging sounds of the metal is also very uncomfortable so yeah so my later experience of the gym meant that I let those things stop me going”.

Equally, Sam and Sarah’s accounts further highlight that auditory sensory sensitivities were characterised by an apathy towards participating in community-based PA. Recollecting a time when they both participated in community-based PA, it became clear that Sam and Sarah’s apathy towards participating in community-based PA derived from auditory sensory sensitivities. For example, Sam described that the “music blaring” limited his desire to participate in community-based PA environments and further influenced his preference to participate in individual forms of PA that were not situated in CBA. Additionally, an apathy towards participating in community-based PA was further reflected by Sarah, who described that community-based PA environments are “too loud” for her to participate in PA in CBA. Although auditory sensory sensitivities contributed to limited PA participation in CBA for the autistic adults in this study, as highlighted below, some participants also conceptualised that visual sensory sensitivities were also drivers of their limited PA participation in CBA. I now turn to examine how visual sensory sensitivities shaped PA participation.

### **5.2.2. Visual sensory sensitivities**

Across participants, some accounts brought attention to the fact that visual sensory sensitivities often limited their PA participation in CBA. In analysing the autistic adults PA participation in CBA, it became clear from some participants accounts that reducing the amount of fluorescent and unnatural lighting in community-based PA environments may lead to increased PA participation in CBA. For example, when asked about ways to improve community-based PA environments, Haley described that the fluorescent and unnatural lighting in community-based PA environments are “absolutely awful” and that her inclination towards participating in community-based PA may be encouraged by the presence of more “natural lighting”. Narratives of a need to minimise the amount of fluorescent and unnatural



lighting in community-based PA environments as a means to encourage future PA participation in CBA were further echoed by Ellen and Sarah's accounts. For Ellen, her experience of visual sensory sensitivities in community-based PA was likened to "a panic room environment", and she further described the need to be able to see more natural "light and trees" to encourage future PA participation in CBA. Ellen also highlighted that she felt that "there's very few" community-based PA environments where you can see natural lights and trees, which in turn limited her desire to participate in PA in CBA. Sarah's narrative further highlights that future PA participation in CBA may be encouraged by minimising the number of "white lights" in community-based PA environments. Importantly, the accounts described by the autistic adults suggest that if community-based PA environments were more conducive to their visual sensory sensitivities, that their PA participation in CBA may increase. Although there were several accounts that highlighted how PA participation in community-based PA could be enhanced by more conducive visual stimuli, some participants accounts further highlight that their apathy towards participating in community-based PA was also influenced by tactile sensory sensitivities. It is to this discussion that I now turn.

### **5.2.3. Tactile sensory sensitivities**

Across the accounts, two participants described that their apathy towards participating in community-based PA derived from tactile sensory sensitivities. In recollecting difficulties with participating in community-based PA, Anna described experiencing discomfort from tactile sensory sensitivities when transitioning "between wet and dry". In a similar vein, Sam's account further highlights that tactile sensory sensitivities were drivers of some of the autistic adults limited participation in community-based PA. While it was clear that Anna's apathy towards participating in community-based PA derived from transitioning between wet and dry, Sam's apathy towards participating in community-based PA derived from the material of "the carpets" that are typically located in CBA. Highlighting the impacts of tactile sensory sensitivities, Sam later described that his limited participation in community-based

PA was influenced by not being able to “face” tactile sensory sensitivities. For some autistic adults in this study, their limited participation in community-based PA was further influenced by olfactory sensory sensitivities. Given the experiences described by some participants, I now turn to discuss how olfactory sensory sensitivities shaped PA participation.

#### **5.2.4. Olfactory sensory sensitivities**

Olfactory sensory sensitivities were identified as playing a role in shaping two autistic adults limited participation in community-based PA. In analysing the accounts, for Jude and Lindsey olfactory sensory sensitivities were characterised by feelings of overwhelm and further influenced their limited participation in community-based PA. While Jude and Lindsey’s olfactory sensory sensitivities derived from different sources, their accounts bring attention to the fact that for some autistic adults in this study, olfactory sensory sensitivities were particularly challenging when participating in community-based PA. In recollecting her experience of participating in community-based PA, Jude described feeling overwhelmed by the “rubbery smell” of trainers and treadmills. For Lindsey, his apathy towards participating in community-based PA derived from olfactory sensory sensitivities with synthetic fragrances. Lindsey described that his limited participation in community-based PA was influenced by his experience of olfactory sensory sensitivities from “perfumes, deodorants, (and) soap powders”. To this point, we have examined how auditory, visual, tactile, and olfactory sensory sensitivities operate in isolation to shape PA participation among autistic adults. However, as illustrated from the accounts above, many autistic adults accounts highlight that their limited participation in community-based PA was influenced by multiple sensory sensitivities. Given the experiences described, I now turn to discuss how the interplay of multiple sensory sensitivities shaped PA participation among autistic adults.

#### **5.2.5. The interplay of multiple sensory sensitivities**

The interplay of multiple sensory sensitivities played an important role in shaping participation in community-based PA for some autistic adults in this study. By an interplay of

sensory sensitivities, we mean that multiple sensory sensitivities interconnected to influence some autistic adults participation in community-based PA. The insights described below are important as they demonstrate that intrapersonal processes (such as motivation) interconnected with environmental processes (i.e., community-based PA spaces) to shape the autistic adults PA experiences and participation. For example, Valerie's narrative highlights how a lack of congruence between her multiple sensory sensitivities and community-based PA spaces not only impaired her desire to participate in community-based PA but were also mentally demanding. When asked about her experience of sensory sensitivities, Valerie likened her experience of multiple sensory sensitivities to "a really complex math problem and it's using all your mental energy it's like trying to do ten of those at once". Whereas Valerie's account highlights that multiple sensory sensitivities often debilitated her mental facilities when participating in community-based PA, Mary's account brings attention to the fact that sensory sensitivities still occur when PA participation in CBA is associated with feelings of enjoyment and pleasure. When reflecting on her PA participation in CBA, Mary described being unaware "that sensory sensitivities (can) even happen if you're enjoying it". Given the experiences mentioned above, it is unsurprising that the autistic adults in this study often engaged in individual forms of PA (e.g., walking) that were not situated in CBA. Although PA participation in CBA was shaped by sensory sensitivities, the personal trainer's style of coaching was also identified as an important process that shaped autistic adults PA participation. The theme highlights how, for the autistic adults in this study, PA participation was shaped by microlevel interpersonal and policy-level dimensions of the personal trainer's style of coaching. It is to the second theme we now turn.

### **5.3. Theme two: personal trainers' style of coaching**

#### **5.3.1. Interpersonal dimensions of the personal trainer's style of coaching**

Across the interviews, experiences with the personal trainer's style of coaching was an important process that shaped their PA participation. In recollecting their previous

experiences of working with personal trainers, autistic adults shared that the personal trainer's notions of health and exercise often conflicted with their reasons to participate in PA. To this end, some autistic adults voiced that personal trainers PA practices were too oriented around altering bodily aesthetics and physical performance rather than promoting the principles of wellness through their PA practices. Although the reason(s) why the autistic adults in this study participated in PA varied (such as alleviating mental health symptoms (Sam, Brandon, Sarah, Colin, Kathleen, Stacey) or for enjoyment (Valerie, Brandon, Haley, Georgia, Ellen, Cassie, Lindsey), for some autistic adults, the predominant focus on aesthetic appearance, winning, and/or competition imposed by personal trainers made their PA experiences arduous and in turn limited their PA participation. The notions of health and fitness imposed by personal trainers made these autistic adults PA experiences arduous, as it left the autistic adults in this study unable to develop lasting fruitful interpersonal as they often felt misunderstood by personal trainers. These experiences are significant as they demonstrate that the autistic adults ability to develop lasting fruitful interpersonal relationships with personal trainers was in part, curtailed by the mutual challenges in communication and understanding that commonly occurs when neurodivergent individuals interact with neurotypicals. These experiences of misunderstanding between autistic adults and personal trainers were also attributed to their overall lack of interest of participating in PA with a personal trainer. For eight participants, these interpersonal dimensions contributed to their overall feelings of scepticism and incertitude towards personal trainers because they believed that personal trainers were unable to adapt their programmes to account for their needs and interests. These experiences in turn shaped their apathy towards participating in PA with a personal trainer. This was illustrated by Hayley, who highlighted that her scepticism towards personal trainers derived from their predominant focus on "losing weight". Although Haley regularly participated in PA, her opportunities to participate in different forms of PA was limited by the personal trainer's predominant focus on aesthetic appearance. This is

significant for Haley, as participating in community-based PA (i.e., weight training) under the guidance of a personal trainer could be used as a vehicle to alleviate the symptoms of her co-occurring conditions. In a similar vein, Sarah's account reveals that her PA participation was also hindered by the personal trainer's predominant focus on aesthetic appearance and adherence to societal stereotypical notions of health and fitness. As a result of this previous experience, Sarah was contemptuous of personal trainers as she felt they were unworthy of her attention. This is significant because Sarah later voiced that the practices of personal trainers needed to be changed in order to support her future PA participation. When asked about ways to improve the practices of personal trainers, Sarah emphasised the need for personal trainers to move beyond assuming that clients are interested in working with a personal trainer because they believe they are "too fat". This predominant focus on bodily aesthetics was a key consideration in order to support the PA of autistic adults in this study. On the other hand, for some participants, the predominant focus on winning and/or competition imposed by personal trainers conflicted with their reasons to participate in PA. For five participants, this conflict often made it arduous to participate in PA with a personal trainer and resulted in a complete avoidance of certain forms of PA. For example, Anna, Barbra, Kathleen, Lindsey, and Sarah highlighted that the incessant emphasis on winning and/or competitiveness contributed to their apathy towards working with personal trainers. Highlighting the impact of the incessant emphasis on winning and/or competitiveness imposed by personal trainers during PA, Barbra noted:

"There was another instructor who was totally obsessed with how I would be beating my personal best... he was running alongside me but he was just push, push, pushing... (he kept saying) you're gonna get your PB you're gonna get your PB and (I) wasn't bothered about my PB I'm not one of those people who can beat a PB if I just got a similar (time) I'm happy"

The aforementioned accounts suggest that PA participation for some autistic adults in this study was not a behaviour solely influenced by intrapersonal processes. Rather, intrapersonal

processes (such as motivation) interconnected with micro-level interpersonal processes (the personal trainer's style of coaching) to shape PA participation. This is critical because this interconnected understanding of autistic adults PA participation suggests there is a need to examine how the multi-level processes associated with PA participation interconnect rather than how they operate in isolation. Although the micro-level interpersonal dimensions of the personal trainer's style of coaching contributed to the limited PA participation among autistic adults, as described below, for some autistic adults, their PA participation was further shaped by the policy-level dimensions of the personal trainer's style of coaching. It is to this discussion I now turn.

### **5.3.2. Policy-level dimensions of the personal trainer's style of coaching**

In addition to the interpersonal dimensions described above that shaped PA participation, some of the autistic adults in this study noted that policy-level dimensions of the personal trainer's style of coaching also played an important role in shaping their PA participation. By the policy-level dimensions of the personal trainer's style of coaching, we mean a systematic lack of awareness among personal trainers about delivering PA to autistic people who commonly have additional needs (such as sensory processing differences, dyspraxia, and/or arthritis). For participants in this study, it was common that they experienced additional cooccurring health conditions such as: Arthritis, Attention deficit hyperactivity disorder, Dyspraxia and Ehlers Danlos syndrome. These co-occurring health conditions played a significant role in their PA experiences of working with personal trainers. For example, some autistic adults habitually stated that many personal trainers were unable to adapt their instructional methods to accommodate to their needs, interests, and abilities. For many autistic adults, it was evident that they experienced difficulties when performing certain activities because of their co-occurring health conditions. Instead of adapting the exercises to accommodate to their needs, it was clear from their previous experiences that personal trainer's would overlook how their co-occurring health conditions impacted their PA

participation. For seven participants, this inability to adapt their instructional methods was attributable to a lack of knowledge among personal trainers about delivering PA to autistic people. This systemic lack of knowledge among personal trainers about working with autistic clients served as a barrier to PA participation. This lack of knowledge, however, was concerning as it detracted opportunities to be active. The lack of knowledge among personal trainers about delivering PA to autistic clients was articulated by Anna, who remarked:

“I think... my biggest kind of issues was I don't think that (the) person doing (it) made them very individualised, and I don't think he ever had an awareness of things like dyspraxia... (i felt like) I shouldn't be teaching you (the personal trainer) how to show exercise to people with additional needs; that's your job”

Some of the autistic adults in this study also further identified the need to increase personal trainers awareness and knowledge about delivering PA to autistic people to increase their future PA participation. Across the participants accounts, it was evident that personal trainers needed general training on how to deliver PA to neurodiverse clients and how to tailor activities that are congruent to their diverse needs and interests in order to increase their PA participation. Despite identifying the aforementioned as a prerequisite to increase their future PA participation, there was no consensus among the autistic adults in this study about which training would adequately support personal trainers to accommodate to their needs, interests, and abilities. In this vein, Sarah, Haley, and Colin broadly acknowledged that having a personal trainer who was adequately trained to deliver PA to autistic clients could be used as a tool to increase their future PA participation. On the other hand, Harry's narrative highlights how there is a need to combat the entrenchment of the bio-medical paradigm of ASD in sport and PA practices as a means to increase his PA participation. To this end, Harry stipulated that it is important to move beyond the bio-medical conceptualisation of ASD by providing

personal trainers with innovative training and awareness through a neurotypical lens. When asked about whether having a personal trainer who was trained to work with autistic clients would increase his PA participation, Harry stated:

“So if the personal trainer had that training from a regressive old fashion(ed) probably delivered by a neurotypical in a medical model, then no (it would not)”

Although the microlevel interpersonal and policy-level dimensions of the personal trainer's style of coaching are presented independently, it is important to recognise that these dimensions interconnected to shape PA participation among autistic adults. As illustrated by the third and final theme, for the autistic adults in this study, trust was highlighted as an important process that shaped their PA participation. The third theme highlights how PA participation among autistic adults was mediated by trust. It is to the third theme that we now turn.

## **5.4. Theme three: Trust**

### **5.4.1. Interpersonal dimensions of trust**

At the interpersonal level, trust was highlighted across some of the participants interviews as an important process that shaped their PA participation. In recollecting their childhoods, some autistic adults shared that they experienced traumatic life events that predominantly occurred in school-based settings that negatively influenced their trust towards participating in PA with other people. For four participants, these traumatic life events (such as bullying and sexual violence) manifested in childhood but continued to impact their PA in adulthood. These traumatic life events, in turn, shaped the difficulties that some autistic adults associated with participating in group-based PA. This was illustrated by Georgia's narrative.

Highlighting the impacts of bullying in physical education classes, Georgia highlighted:

“I think... the effect of bullying and confidence with sport with strangers... I think that is a big thing of it is the fact other people are watching you (I) don't know them when I say don't



know them I mean I don't know them really well (I) don't trust them or they haven't got my trust and that makes it really hard I think that's just scars.”

This traumatic life event negatively impacted Georgia's outlook towards strangers in PA spaces and limited her opportunities to participate in PA. In a similar vein, Mary's account reveals that her pessimism towards personal trainers derived from the effects of bullying in physical education classes. When asked about the effects of bullying, Sarah remarked that her distrust towards other personal trainers who adhere to desirable societal stereotypical notions of health derived from “the whole PE teachers fit girls thing (in PE) ... (women) are intimidated by someone who looks like one of their school bullies”. Although Sarah worked as a personal trainer and was highly physically active, her perspective is critical as it demonstrates that her mistrust towards personal trainers derived from the fear of being retraumatised by the effects of childhood bullying. Some autistic adults found that the challenges posed by their neurodivergence exacerbated the impacts of these previous traumatic life events. By the challenges posed by their neurodivergence, we mean that some participants highlighted that being autistic made it more challenging to process the impacts of these traumatic life events. From their experiences, Ellen and Jude shared that these traumatic childhood experiences not only negatively influenced their trust towards their everyday adult lives but also decreased opportunities to be physically active. These insights provided by Ellen and Jude are significant as they demonstrate that the effects of childhood traumas remain pervasive in many aspects of their lives. This was illustrated by Jude, who highlighted how the effects of childhood bullying impacted her life:

“(Because I was bullied as a child in PE) there’s no way I was ever going near a trampoline until I was with the bairn<sup>2</sup> until he was little... (because bullying affected my self-esteem) I can't do hairdressers and I think it's mostly (because of) the mirror”

The insights described above are significant as they suggest that for some of the autistic adults in this study PA participation was mediated by the interpersonal dimensions of trust. Importantly, the accounts suggest there is a need to introduce strength-based approaches that aim to build and support trust between PA deliverers and autistic adults in order to provide them with more opportunities to be physically active.

As illustrated across the three themes, PA participation for the autistic adults in this study was a behaviour that was influenced, hindered, and/or shaped by interconnected processes between the intrapersonal, interpersonal, environmental, and policy-level of the social ecological model. These interconnected processes shaped PA in various ways, and the findings of this study provide valuable contributions to the field of autism research. Now that I have outlined and described the results of this study, I now turn to outline and describe the discussion and conclusion chapter of the thesis to place the findings of this study into context.

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<sup>2</sup> In the Northeast of England, the word “bairn” is a form of colloquialism that is generally used to refer to a child or baby. In the context of Jude’s narrative she highlights how her fear of being judged when trampolining with her child derived from the impacts of childhood bullying.

## Chapter 6

### 6.1. Discussion and Conclusion

To the author's knowledge, this is the first qualitative study conducted in the UK with autistic adults that were 35 years of age and older to examine the processes that influence, hinder, and/or shape their PA participation. Gathering first-hand perspectives from autistic adults ( $\geq$  35 years) to understand their PA participation is important because their perspectives have been relatively absent from research. Conducting research in this area is important as it may allow us to augment our understanding of the processes that influence, hinder, and/or shape autistic adults PA participation. This research contributes new knowledge to the literature by adding depth and nuance to the understanding of PA participation with autistic adults. To date, much of the research examining PA participation has been conducted with autistic children and adolescents (Piven & Rabins, 2011), proxy stakeholders (e.g., parental perspectives) (See for example Nichols et al., 2018), and/or young autistic adults (Waldron et al., 2022). Furthermore, there is also a lack of research examining how intrapersonal processes interconnect with interpersonal, environmental, and policy-level processes to shape autistic adults PA participation. Given these knowledge gaps, the results of this work are significant as they demonstrate that interconnected processes shaped PA participation for the autistic adults in this study. Notably, the findings of this study suggest that PA participation for autistic adults was a behaviour shaped by several interconnected processes between the intrapersonal (sensory sensitivities), interpersonal (trust), environmental (sensory sensitivities), and policy level (personal trainers' style of coaching) of the social ecological model. This ecological understanding of PA is important as the study findings illuminate that PA participation was not a behaviour solely influenced by intrapersonal processes such as motivation or self-concept. Rather, for the autistic adults in this study, sensory sensitivities, the personal trainer's style of coaching, and trust were interconnected to influence, hinder, and/or shape PA participation. This interconnected understanding of PA participation among autistic adults described in this study provides a valuable contribution to the field of autism

research as it highlights the need to understand the multi-level processes associated with PA participation. The results of this work suggest that future research should focus on how the multi-level processes associated with PA among autistic adults interconnect to shape PA participation rather than focusing on how these processes function independently to shape PA participation.

As will become apparent below, PA participation for the autistic adults we worked with was influenced, hindered and/ or shaped by three interconnected processes. These interconnected processes were *sensory sensitivities*, *the personal trainers style of coaching* and *trust*.

Although experiences of sensory sensitivities seem to be unique processes that influence neurodivergent peoples PA behaviours (e.g., Skalitzky, 2023; Blagrove et al., 2021), the challenges associated with the personal trainers style of coaching and trust are consistent with the reported processes that shape the general populations PA participation (e.g., Harcourt et al., 2020; Fox & Lindwall, 2014).

One of the salient processes which impacted PA was the impact of sensory sensitivities.

Although there is a growing body of research examining how sensory sensitivities shape PA participation among autistic children and adolescents (Duquette et al., 2016; Askari et al., 2014; Healy et al., 2013; Hochhauser & Engel-Yeger, 2010), there is a paucity of research examining how sensory sensitivities shape PA participation among autistic adults. Apart from two studies that have identified sensory sensitivities as a process that shapes PA participation among autistic adults (Blagrove et al., 2021; Nichols et al., 2018), sensory sensitivities have been omitted as a process that can shape PA participation among autistic adults. The studies carried out by Blagrove and colleagues (2021) and Nichols and colleagues (2018) demonstrate that sensory sensitivities are ascribed by autistic adults as an important factor in determining the success and enjoyment of PA experiences. However, the findings of this study demonstrate that sensory sensitivities were a common experience among autistic adults that not only adversely impacted the success and enjoyment of PA experiences but in turn

limited opportunities to be physically active. Although the impacts of sensory challenges have been extensively documented for autistic people across the life course (Jones et al., 2020; Zickgraf et al., 2020; Pellicano, 2013), research has overlooked the impacts sensory challenges can have on sport and PA participation and experiences. The apparent absence of research exploring the impacts sensory challenges can have on autistic people's sport and PA participation is enigmatic, given that research suggests that between 53.6% (Jussila et al., 2019) to 94% (Leekam et al., 2006) of autistic people experience sensory differences. With this in mind, it is critical for future research efforts to be targeted at exploring the impacts of sensory challenges on autistic people's sport and PA participation in order to better support their overall PA participation. Given the findings of this study, we suggest that there is a need to abate the experiences of sensory sensitivities in order to increase autistic adults PA participation. As a potential point of departure, future research could work with local councils to assess the viability of adapting community-based environments to meet the sensory needs of autistic adults. To increase the impact of this research, autistic adults with lived experience of sensory sensitivities could provide guidance on how to make community-based environments better suited to their needs and preferences. To achieve this aim, we suggest that future research efforts should be steered towards co-producing a training tool with autistic adults to increase commercial gyms members of staff's understanding of sensory sensitivities and how to make appropriate adaptations in community-based spaces to support their PA participation. These efforts are not only needed to protect autistic adults from the deleterious impacts of sensory sensitivities but are also needed to increase opportunities for autistic adults participate in PA in community-based spaces.

In addition to reducing sensory sensitivities to increase future PA participation, the results of this work suggest that the current pedagogical practices of personal trainers was another pertinent process that impacted autistic adults PA participation. In alignment to Duquette and colleagues (2016) findings among autistic youth, the autistic adults in this study voiced that

personal trainers were not adequately trained to promote PA with autistic clients. For these particular autistic adults, the perceived lack of awareness and training among personal trainers made their PA experiences arduous, as it left personal trainers unable to adapt their instructional methods to accommodate to their needs, interests, and abilities. Furthermore, these particular autistic adults ascribed that the perceived lack of awareness and training among personal trainers served as a significant barrier to PA participation, which in turn limited opportunities to be physically active. Given the significant role that the awareness and training among personal trainers played in the autistic adults PA participation and experiences, the findings of this study suggest that there is a need for future work to introduce innovative pedagogical practices among personal trainers to increase autistic adults PA participation. Given that in the UK there is no policy-level education and training offered to personal trainers to increase their awareness of promoting PA with disabled clients (DeLyon et al., 2016), we suggest there is a need to introduce a mandated national-level training awareness course that focuses on educating and teaching personal trainers about some of the challenges that autistic people experience (such as sensory sensitivities and autistic burnout) and how to adequately adapt training sessions to meet the needs of autistic adults to increase future PA participation. As a potential point of departure, future research could collaborate with policy makers to ensure that educational and funding pathways are targeted at increasing personal trainers' awareness of working with autistic clients. This is critical to not only ensure this supports their PA, but also ensures that PA does not further marginalize or exclude (Nicholls et al., 2018) vulnerable groups such as autistic people.

The findings of this study also highlighted that trust was an important process that shaped PA participation among autistic adults. Although the concept of trust has been briefly identified as a process that can shape PA participation among autistic children and adolescents (Haegele et al., 2023; Arnell et al., 2017), the concept of trust has not been explored as a process that can shape PA participation among autistic adults. Problematically, some autistic adults

narratives in this study highlighted that mistrust, especially towards those promoting or delivering PA, was highly prevalent. This in turn limited their PA participation. These particular autistic adults generally experienced difficulties trusting those who were employed to deliver PA (e.g., personal trainers and physical education teachers). Trust, however, can have an important impact on autistic adult's interpersonal relationships with other people (Pearson et al., 2022; Pearson et al., 2022). Given the importance of trust highlighted by participants in this study, we suggest that there is a need to introduce innovative concepts that predominantly focuses on building and supporting trust among autistic adults to increase their PA participation. As a potential point of departure, there may be value in building a therapeutic alliance (TA) between those employed to deliver PA and autistic adults to support their PA participation and to guide PA practices. Although the definition of a TA remains ambiguous (Ardito & Rabellino, 2011), a TA can be conceptualised as a transtheoretical concept that aims to build trust and rapport between a patient and their therapist in order to achieve positive behavioural change (Saketopoulou, 1999). Originally proposed as a psychotherapeutic concept, evidence suggests that a strong TA can improve the outcomes of therapy (Cameron et al., 2018; Arnow et al., 2013; Horvath et al., 2011). As outlined by Bordin (1979), a TA is based upon three core interconnected principles. Firstly, in order to increase a TA between a patient and their therapist there needs to be a degree of mutual trust, collaboration, and acceptance. Secondly, as part of the TA process the patient and their therapist need to come to an agreement about the activities that they will carry out together during therapy. Third and finally, a patient and their therapist need to mutually agree on the goals of therapy. With these core principles in mind, it may be beneficial to build a TA between autistic adults and those employed to deliver PA given that trust played a significant role in the autistic adults PA participation and experiences. With two studies suggesting that TA can potentially facilitate trust between participants and healthcare providers (Hume, 2022; Hume, 2022), future research should employ the concept of TA to assess the viability

of building a TA between PA deliverers and autistic adults as a means to increase their PA participation. As a potential point of departure, future research could conduct a viability study with autistic adults and various deliverers of PA (such as personal trainers, physical education teachers, and community sports coaches) to evaluate the efficacy of applying the concept of TA in the sport and PA settings.

## **6.2. Study limitations**

Despite the many strengths of this study, there are a few limitations and considerations which prompt the need for further research. First, the study sample was limited to the perspectives and experiences of verbal autistic adults. Although their perspectives provided critical insights into their experiences with PA which heretofore has been limited, future research needs to include participants who communicate in ways other than verbal speech as between 25-30% of autistic people are non-verbal (Hinzen et al., 2019). Including their perspectives is vital as there is a significant dearth of research in this area, yet is much needed to gain an in-depth understanding of their PA participation. Second, the study sample was predominantly comprised of females, with a noticeable gap in participants who identified as male, and diverse identities. While it is critical to include the perspectives of autistic females as their voices have been excluded from PA research (Jachyra, 2023), it is important for future research to prioritize gender diverse samples in an effort to support the PA needs and interests of all autistic people. This is of particular importance as emerging research suggests that autistic adults are more likely to have diverse gender identities when compared to non-autistic adults (Weir et al., 2021). Third, the study sample was limited to the perspectives and experiences of middle-aged autistic adults (<65 years). Their perspectives provided critical insights into PA participation which have not been extensively described as much of the PA research has focused on children and youth (Piven & Rabins, 2011). Importantly however, there is a need for research to be conducted with older autistic adults as there is very limited knowledge in this area, along with a limited understanding on how to support their PA and



well-being. Research in this area is timely and significant particularly for the lost generation of autistic adults who historically may have been undiagnosed or misdiagnosed (Lai & Baron-Cohen, 2015), yet potentially would be in need for further support. Conducting research with this group is important to develop a more comprehensive understanding of PA participation for autistic people across the life-course, which is currently a significant gap in research, policy and practice. Fourth, the study sample was limited to the perspectives of autistic adults from the UK. Their perspectives provided important contextual insights regarding PA participation in the UK which have not been extensively described across the literature. However, it is of paramount importance for future research to be conducted with autistic adults from different contexts and countries. Gathering perspectives from autistic adults from different contexts and countries is critical as they likely have different life experiences and perspectives. Fifth and finally, another notable limitation of this study was the absence of a data saturation plan. While our qualitative approach allowed us to ascertain an in-depth understanding of autistic adults from the UK experiences of PA which has not been extensively described across the literature, it is important to note that the absence of a data saturation plan may have curtailed the validity and generalisability of the study. We therefore suggest that future studies should implement a rigorous data saturation strategy in order to ensure diverse perspectives and analysis are captured to enhance our understanding of autistic adults experiences of PA.

### **6.3. Conclusion**

This study examined the processes that influenced, hindered, and/ or shaped PA participation among autistic adults. Given that there is a paucity of research examining PA participation among autistic adults, the study findings contribute to the field of autism by providing a more comprehensive understanding of the processes that interconnect to shape PA participation among autistic adults. The findings suggest a need to reduce sensory sensitivities, introduce innovative pedagogical practices among personal trainers, and to potentially introduce the

concept of TA between autistic adults and PA deliverers in order to increase PA participation. These efforts are needed in order to help autistic adults to be physically active.

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## **Appendix Items**

### **Appendix-A Participant information Sheet**

#### **Participant Information Sheet**

Study title: An examination of the perspectives of autistic adults about their engagement in physical activity.

#### **Section 1-Background**

## **1.1 Invitation and brief summary**

You are invited to take part in this study which will explore your participation in physical activity. You have been invited to take part in this study as you are an adult who is at least thirty-five years old who currently resides in the United Kingdom and have been diagnosed or self-diagnosed with either of the following conditions: Autism, Pathological Demand Avoidance (PDA), Asperger's syndrome, Autistic Disorder or Pervasive Development Disorder (PDD). This study has been reviewed by the Durham University Sport and Exercise Sciences Ethics Committee, and the associated risk assessment has been approved by the Department of Sport and Exercise Sciences Health and Safety Committee.

## **1.2. Why have I been invited to take part?**

You have been invited to take part in this study because you are an older autistic adult who is at least 35 years old who currently resides in the North-East of England. If you meet the criteria for the study, you will have the opportunity to participate. The criteria to participate in this study is detailed below: Inclusion Criteria: • Individuals who reside in the United Kingdom who have been identified as having autism or another pervasive developmental condition • who is at least 35 years old • Ability to communicate verbally • Provide informed consent

## **1.3. Do I have to take part?**

The decision to take part in this study is completely up to you and should you decide to take part, you are free to withdraw at any time without giving a reason. If you decide to take part, you will be given this information sheet to keep for your further reference and you will be asked to sign a consent form. You will be able to ask questions about the study at any time before, during or after the study.

## **1.4. Why are you doing this research?**

Physical activity can be enjoyable and offer many social, health and psychological benefits. Despite the benefits, autistic people are less likely to be active. No previous research has included the perspectives of autistic adults regarding their engagement in physical activity. There is a need for this research to better understand how to support the physical activity of autistic adults.

### **1.5. What is involved?**

If you decide to take part, you will be invited to complete two interviews. You will have the option to decide if you would like to complete the interview online or in person. During the first interview we will discuss what participating in the study will look like. Secondly, we will work together to see if you consent to participate in the study and will discuss with you your personal interests and hobbies. The first interview will last about 30 minutes. At the end of the interview, we will find a time to meet again and discuss your experiences and perspectives of physical activity. The second interview will last between 60-90 minutes. Important: If you require assistance, you are welcome to have someone attend the interviews with you.

### **1.6. What are the possible benefits of taking part?**

Your participation in this research will offer new perspectives that will expand our understandings of autistic adults' engagement in physical activity. There is a need for this research to better understand how to support the physical activity of autistic adults

### **1.7. What are the possible risks of taking part?**

All procedures used in this study are routinely conducted in research and extensive ethical considerations have been reviewed and subsequently approved by Department of Sport and Exercise Sciences Health and Safety Committee. If you experience any distress or discomfort during the interviews, please notify the researcher (James). During the interview, you will be provided with the opportunity to take a break, choose not to answer a question, come back to a certain point of conversation or can end the interview at any moment.

## **Section 2 - Supporting information**

### **2.1. What if something goes wrong?**

All procedures used in this study are routinely conducted in research. In the event you experience any problems that may be caused by this study, please tell any member of the research team (Outlined in section 4). In the event that it is necessary, we will direct you to seek further support from your local general practitioner or by calling 111.

### **2.2. What if I don't want to continue with the study?**

If you decide that you no longer wish to take part in the study, please contact a member of the research team as soon as possible (Outlined in Section 4). You can withdraw from the study at any time.

### **2.3. Will my taking part in the study be kept confidential?**

All data collected will be kept strictly confidential to the immediate research team. Data included in reports will not have your name and other identifying information.

### **2.4. What will happen to the results of the study?**

The results will be written up for an internal report and may be written up for publication, presented at a conference or submitted as an abstract and subsequent presentation.

### **2.5. Who is involved and who is funding this study?**



This study will be supervised by Dr Patrick Jachyra and Professor Martin Roderick from Durham University. The study has received funding from the National Institute for Health Research.

## **2.6. Who has reviewed the study?**

This study has been reviewed by the Durham University Sport and Exercise Sciences Ethics Committee.

## **Section 3 - Data Protection**

### **3.1. What type of data will be collected?**

How will my data be stored and processed? All information will be collected and stored in accordance to the GDPR, 2018. Personal data obtained will be processed for purposes incompatible to this study and personal data will be relevant and not excessive in relation to the purpose of this study. All data will be anonymised using participant codes and stored in a secure location on password protected files, which will be available to named researchers. The data will be collected on the lawful basis through provision of participant consent.

### **3.2. How to object to the processing of your personal data?**

If you have any concerns regarding the processing of your personal data (Outlined in the privacy notice), or you wish to withdraw your data from the project, please contact the research team (Outlined in Section 4).

## **Section 4 - Further information and contact details**

### **4.1 How to contact the research team?**

If you have any further questions related to this study or your participation, please contact a member of the research team on the following contact details:

Mr James Mcleod, email: james.mcleod@durham.ac.uk Office address: 4 Green Lane,  
Durham University, Durham, DH1 3JU

Dr Patrick Jachyra (Primary Supervisor), email: [patrick.jachyra@durham.ac.uk](mailto:patrick.jachyra@durham.ac.uk) Office  
address: 4 Green Lane, Durham University, Durham DH1 3JU

Dr Martin Roderick (Secondary Supervisor), email: [m.j.roderick@durham.ac.uk](mailto:m.j.roderick@durham.ac.uk) Office  
address: 4 Green Lane, Durham University, Durham DH1 3JU

#### **4.2. Additional resources**

1) Additional information about Durham University's responsibilities for data protection and your rights in relation to personal data can be found in Durham University's generic privacy notice, available at:

<https://www.dur.ac.uk/research.innovation/governance/privacynotice/generic/>

2) Additional information about Dr Patrick Jachyra can be found on Durham University's staff profile page, available at: <https://www.durham.ac.uk/staff/patrick-jachyra/>

3) Additional information about Dr Martin Roderick can be found on Durham University's staff profile page, available at: <https://www.durham.ac.uk/staff/m-j-roderick/>

#### **Appendix B- Recruitment Flyer**



## Autistic Adults Experiences with Physical Activity, Sport, and Exercise

### Who can Participate?



1) Adults who are **45 years of age or older** and live in the **United Kingdom**

2) Adults diagnosed **OR** self-diagnosed with:

- Autism
- Asperger Syndrome
- Self-identify as Autistic
- Pervasive Developmental Disorder-Not Otherwise Specified

Study Approved by  
Durham University  
Ethics Committee



### What's Involved?



1) Two **interviews** to discuss your experiences with physical activity/sport/exercise

2) Interviews can be conducted **online** or in **person**

**£20 voucher** after completing the study

### Why this Study?



1) Work together to support physical activity among autistic adults

2) Participating in the study will take **1 hour** of your time

To participate or for more information please contact James Mcleod or Dr. Patrick Jachyra at:

[james.mcleod@durham.ac.uk](mailto:james.mcleod@durham.ac.uk)  
[patrick.jachyra@durham.ac.uk](mailto:patrick.jachyra@durham.ac.uk)

# How to Access Microsoft Teams



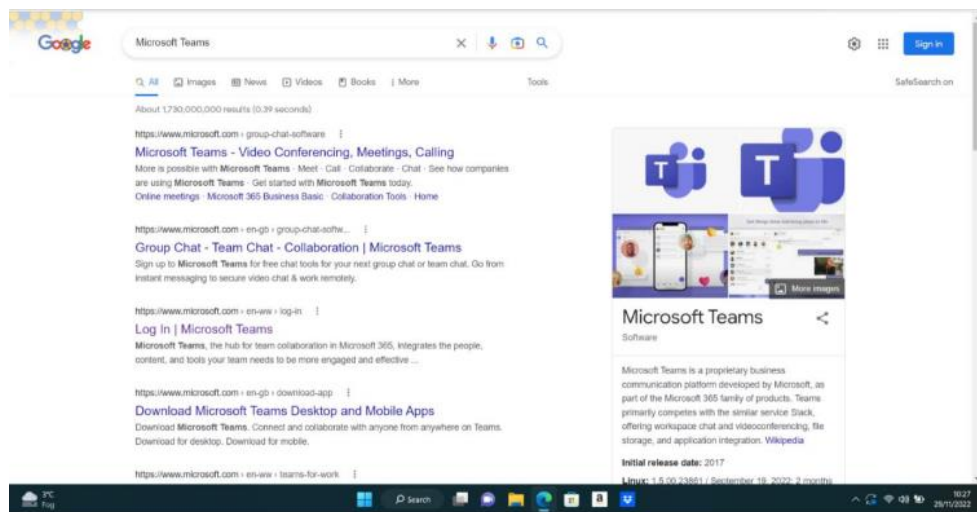
Thank you for helping me with my project. I look forward to talking to you and learning from you.

When we talk online, I will ask you meet on Microsoft Teams. This guide will help you to access and work on Microsoft Teams.

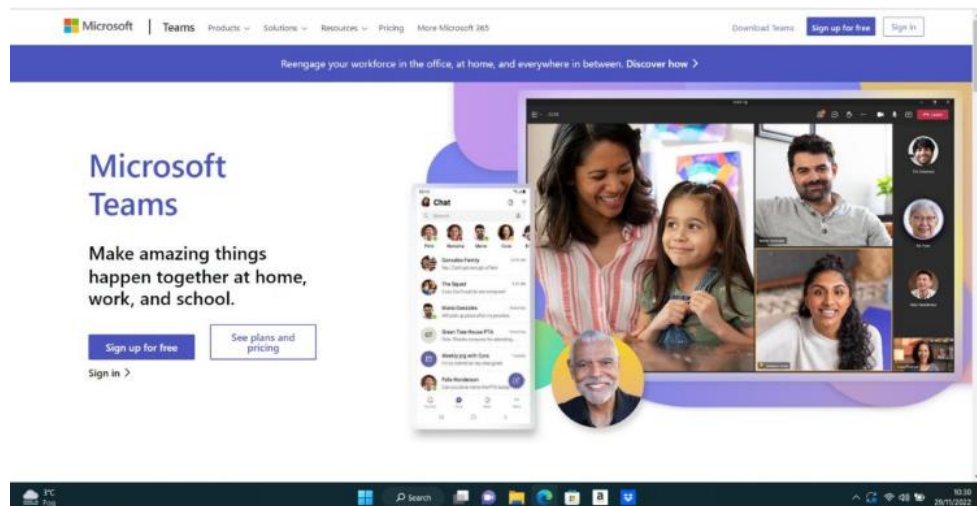


**Step 1:** To start with you will need to type in google into your search bar. The image above shows what you should see on your computer.

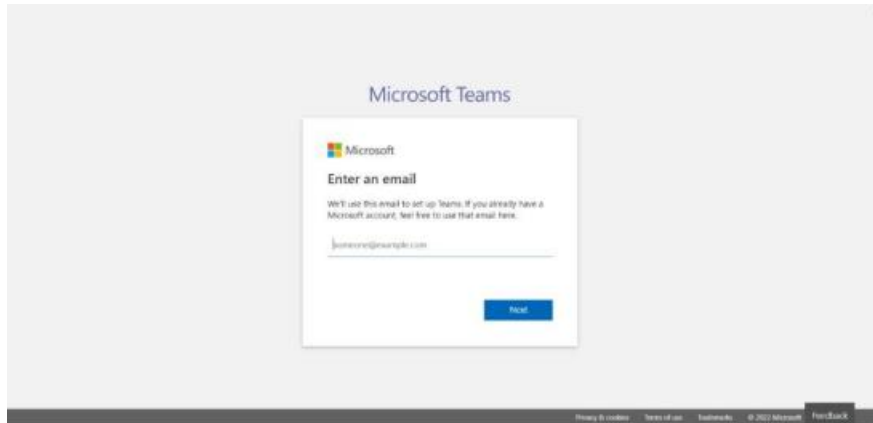
**Step 2:** After this, you will need to type into google “Microsoft Teams” and then click enter on the keyboard. The following screen should come on to your screen.



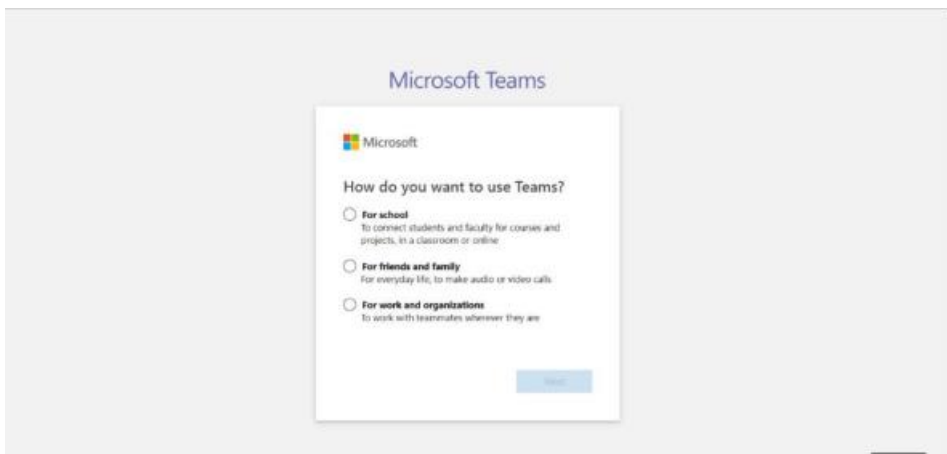
**Step 3:** You then will need to click the first link named “Microsoft Teams- Video Conferencing, Meeting, Calling”. Once you have completed this you will need to click on “sign up for free”.



**Step 4:** Once you have clicked on “sign up for free” you will have to enter an e-mail address to register your account. It will then appear on your screen “How do you want to use Teams”. You will need to select the “For work and organisations” option.



**Step 5:** It will then appear on your screen “How do you want to use Teams”. You will need to select the “For work and organisations” option.



**Step 6:** You will then need to login to your account by re-entering your e-mail along with a password. To make sure your Microsoft Teams account is secure, enter a password only you, your guardian or caregiver will know.

**Step 7:** You will then need to select the ‘Calendar’ tab where the meeting invite from James Mcleod should be. The calendar tab will be on the left-hand side of the screen.

**Step 8:** To gain access to the meeting you will need to click on the “Online Meeting” which will be displayed with James Mcleod below it. After this it will appear on the screen to “Join Meeting”. You will need to click on this, and the meeting will start.

**Step 9:** If you click on “Join Meeting” and James Mcleod does not seem to be in the call yet, please wait until he appears on your screen. James Mcleod will be attending the meeting; he just might not have joined the meeting at that time.

If you require any further information on how to access Microsoft Teams, please contact James Mcleod on the following e-mail address: [james.mcleod@durham.ac.uk](mailto:james.mcleod@durham.ac.uk)

## **Appendix D: Interview guide: Interview one**



Durham  
University

## Sample Interview Guide

**Produced by:**

**James Mcleod**

**Study Title: An examination of the perspectives of older autistic adults about their engagement in physical activity.**

I want to spend today getting to know you a little better. You and I will each learn a little bit more about each other. During our discussion today we will chat about some of your interests and hobbies.



### **1) About you (Participant)**

What kinds of things do you like to do?

Do you have any activities or interests that you really like?

Are there any activities that make you feel better about yourself? **Probe:** ask what about that activity makes them feel better.

### **2) What does a typical week look like for you?**

Do you have any family members, relatives or pets?

Do you engage in physical activity? **Probe:** where?, who with? How often? How does it make you feel?

Are you currently employed? **Probe:** ask about hours worked per week/ how often they work What do you like about physical activity? **Probe:** Is there anything you dislike?

What about your weekends? Do they look different? **Probe:** What do you do on a weekend?

### **3) About you (The researcher)**

Ask the participant if there is anything they would like to know about me.

**End with thanking them for their time and arranging next interview- Remind them about attending the 2<sup>nd</sup> interview where we will discuss their engagement in physical activity.**

## **Appendix- E. Consent Form Template**

### **Participant Consent Form**

**Project title: An examination of the perspectives of older autistic adults about their engagement in physical activity.**

I voluntarily agree to participate in this research study.

Please read the following before signing the agreement:

- I understand that even if I agree to participate now, I can withdraw at any time or refuse to answer any questions without any repercussions of any kind.
- I understand that I can withdraw permission to use data from my interview, in which case the material will be deleted.
- I have had the purpose, nature and potential benefits of study explained in writing and I have been provided with an opportunity to ask questions about the study.
- I understand that participation involves taking part in either two in-person or online interviews.
- I understand that I will not directly benefit from participating in this research
- I agree to my interview being audio-recorded.
- I understand that all information I provide for this study will be subject to confidentiality and anonymisation. I understand this will be carried out by the

research team by applying pseudonyms where my name or identity of anyone I discuss may be revealed.

- I understand that disguised extracts from my interview may be revealed throughout the primary researcher's master's project and could be subject to publication and subsequently presented at a conference or presentation.

**Signature of research participant**

----- Date -----

**Signature of researcher**

I believe the participant is giving informed consent to participate in this study

----- Date -----

**Further information**

If you have any further questions related to this study or your participation, please contact a member of the research team on the following contact details:

**Mr James Mcleod, email: [james.mcleod@durham.ac.uk](mailto:james.mcleod@durham.ac.uk)**

Office address: 4 Green Lane, Durham University, Durham, DH1 3JU

**Dr Patrick Jachyra (Primary Supervisor), email: [patrick.jachyra@durham.ac.uk](mailto:patrick.jachyra@durham.ac.uk)**

Office address: 4 Green Lane, Durham University, Durham DH1 3JU

**Dr Martin Roderick (Secondary Supervisor), email: [m.j.roderick@durham.ac.uk](mailto:m.j.roderick@durham.ac.uk)**

Office address: 4 Green Lane, Durham University, Durham DH1 3JU

**Appendix F: Interview Guide: Interview two**



**Durham**  
University

**Sample Interview Guide (2)**

**Produced by:  
James Mcleod**

**Study Title: An examination of the perspectives of older autistic adults about their engagement in physical activity.**

I want to spend today to build upon our conversations during our first meeting. I want to specifically discuss your engagement in physical activity today and to explore why you do or do not engage in physical activity. **Probe:** Discussed in previous interview about their physical activity begin by building upon the preferences stated.

**1) You discussed at our last meeting that you engage in physical activity.**

- Why do you engage in physical activity?
- Is there anything about physical activity that makes it appealing to engage in?
- Do you engage in physical activity as much as you would like? **Probe:** Is there anything that prevents you from engaging in physical activity more often?
- How does engaging in physical activity make you feel? (Physically)
- How does engaging in physical activity make you feel? (Emotionally)
- You mentioned that you liked (Insert preference stated in previous meeting) what about this makes you engage in physical activity?
- Is there any forms of physical activity you dislike? **Probe:** why, what about this do you dislike?
- Would you be open to engaging in a different form of physical activity? **Probe:** Which form of physical activity? How could we help you to engage in this?

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**2) I now want to get to know about who you engage in physical activity with and where you tend to engage in physical activity.**

- Do you engage in physical activity on your own? **Probe:** if with someone who with? Why them?
- Does this person encourage you whilst you are engaging in physical activity?
- Where do you typically engage in physical activity? **Probe:** What about this environment do you like? Is there anything about this environment that makes you nervous?
- Have you ever experienced any negative experiences whilst engaging in physical activity?
- Would you change where you engage in physical activity if a friend suggested to? **Probe:** Why not? What about this environment do you not like?
- Is there anything else preventing you from not engaging in different forms of physical activity?

**3) Barriers to Participation**

- Is there anything that you believe prevents you from engaging in physical activity?
- Is there a negative experience(s) whilst engaging in physical activity that stands out for you? **Probe:** What about this experience was negative? How did it make you feel? How did it affect your engagement in physical activity after this event?

Do you believe that the physical activity programmes offered to you meet your needs?

**Probe:** What about these programs need changed? Is there anything about these programmes that you believe should stay the same?

- What personal barriers to participation do you experience? **Probe:** financial barriers? Transport? Bullying and exclusion?
- Do you believe the way in which programmes are delivered have acted as a barrier to your participation? **Probe:** What about the way in which they are delivered do you not like? How can we change the way in which they are delivered to make them more effective?
- Do you believe there is enough physical activity programmes offered to you?

### **General Questions**

- Is there anything else that we haven't talked about today that you think I should know about?
- Is there anything missing to help you become more physically active?

**End Interview by thanking participant for engaging in the research and that you sincerely thank them for their contributions to your research.**