

HYPERFOCUS IN AUTISM: AN EXPLORATION INSPIRED BY THE PRINCIPLES
OF NEURODIVERSITY

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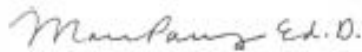


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DISSERTATION ABSTRACT

HYPERFOCUS IN AUTISM: AN EXPLORATION INSPIRED BY THE PRINCIPLES
OF NEURODIVERSITY

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Autism is a condition that affects an estimated 1% of the global population. Current approaches to research and intervention are based on outside observations, thus excluding the input of autistic individuals. Furthermore, most conceptualizations and theories of autism are rooted in a deficit-based framework. The concept of neurodiversity challenges this perspective and argues that features of autism are differences rather than deficits. Hyperfocus is one such experience that has been identified by autistic advocates as not only a difference but also a strength. This study aimed to further the conceptualization of autism by investigating the presence of and lived experience of hyperfocus from the view of autistic adults. Results demonstrated the highest self-reported rate of hyperfocus in autistic participants (with and without co-occurring conditions) and the perception of hyperfocus as beneficial. These findings have widespread implications while supporting a

continued need for advocacy. Future research should continue this exploration of hyperfocus and the neurodivergent lived experience.

Keywords: autism, autistic, neurodiversity, neurodivergent, hyperfocus

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Chapter I

Literature Review

Introduction

While there is impressive and extensive research literature on the identification and treatment of autism spectrum disorders, the lived experiences and attitudes of autistic individuals are rarely the focus of research (Bagatell, 2010; Bradley & Caldwell, 2013; Krcek, 2013; Russell et al., 2019; Woods et al., 2018). Much of the current understanding, research, and treatment procedures surrounding autism are focused on perceived deficits that have been identified by non-autistic professionals. For instance, the American Psychiatric Association (2013) defines autism as a developmental disorder with “persistent deficits” in the areas of communication, social responsiveness, and repetitive behaviors/restricted interests (p. 50). Furthermore, inconsistencies exist between professional representations of autism and the autistic lived experience. According to data collected by the American Psychiatric Association (2013), approximately 1% of the global population meets diagnostic criteria for autism, with the condition being four times more common in males. However, recent research shows that this discrepancy in gender may not be as drastic as initially hypothesized (Cooper, Smith et al., 2018; Lai et al., 2015). Furthermore, the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (*DSM-5*; p. 52) states that there are three levels of autism: the first level includes individuals “requiring support”; the second level includes those “requiring substantial support”; and the third level includes those “requiring very substantial support.” In addition to the outlined levels, autistic individuals tend to be informally categorized as either “low functioning” or “high functioning” depending on

their cognitive abilities (Alvares et al., 2020), though there is little guidance on how to use these classifications and the autistic community reportedly disagrees with these groupings (Kenny et al., 2016; McGeer, 2004).

Although the diagnosis of autism is widely recognized today, the conceptualization and general understanding of this condition is still lacking. The first known mention of autism was in 1911 by Dr. Paul Bleuler in his paper “The Theory of Schizophrenic Negativism,” which proposed that such features were a manifestation of schizophrenia (Kuhn & Cahn, 2004). Bleuler wrote about “autistic withdrawal” based on his observations and experiences with clients. He believed that such withdrawal was a precursor to more severe cases of the negative symptoms seen in schizophrenia. Nearly 30 years after the work of Bleuler, the psychiatrist Leo Kanner published a paper entitled, “Autistic Disturbances of Affective Contact” (Kanner, 1943, as cited in Lyons & FitzGerald, 2007). In the same year, the pediatrician Hans Asperger published his thesis, “Autistic Psychopathy in Childhood.” Their work led to more widespread usage of the term “autism” and laid the foundation for how the field of psychology conceptualized this condition. Regardless, the theories of both men played a significant role in the field of psychology’s understanding of this diagnosis.

Kanner presented two main diagnostic features of what he termed “early infantile autism” during a childhood schizophrenia symposium in 1955 based on the observations of over 120 children being treated at the Children’s Psychiatric Service of Johns Hopkins Hospital (Eisenberg & Kanner, 1956). First, these children displayed “an extreme autistic aloneness” (p. 556) which referred to a lack of interpersonal connectedness. The second feature was described by Kanner as a “preoccupation with the preservation of sameness”

(p. 564). This phrasing was used to describe the presence of repetitive motor movements and insistence of sameness in the child's environment and routine. In addition to his proposed criteria, Kanner stated that these children displayed delays in their language abilities, engaged in rituals and rigid behavior, and displayed a general lack of social understanding. He also described his personal observations of the parents of these children, stating that many of these parents had an above average intelligence, obsessive traits, and a "coldness." Kanner believed that psychotherapy was not effective in the treatment of "early infantile autism" but stressed the importance of a supportive school environment (Eisenberg & Kanner, 1956). This recommendation was based on the improvements observed in autistic children who had been "extended extraordinary consideration by their teachers" (p. 560). Kanner also reported on the strengths of some of these children, noting that they displayed above average intelligence and speech. Simply put, Kanner himself believed that there was much to learn about autistic individuals, how they see the world, and how best to support them clinically. This included an exploration of both strengths and weaknesses.

In Asperger's writings on autism, he came to markedly different conclusions than Kanner. Specifically, Asperger's definition of "autism psychopathy" involved five features: social ineptitude, insistence for sameness, deficits in nonverbal language, self-stimulating behavior, and lack of humor (McLaughlin-Cheng, 1998). Asperger conceptualized these behaviors as a communication disorder and believed that they would persist over time while the individual's intelligence and personality continued to develop typically. Despite the differences between Kanner's and Asperger's theories, their conceptualization of autism was similar. For the most part, autism was viewed as an

impairing disorder with few to no treatment options. However, there was also an acknowledgment of the potential strengths of these individuals (such as typical or above average intelligence).

Despite the similarities between these early conceptualizations, many inconsistencies and inaccuracies in the understanding of autism have developed since its establishment as a separate psychological condition. As stated by Milton (2012b), “Kanner’s work laid the foundation for early accounts of autism, whilst the work of Asperger was left largely undiscovered until the 1970s. Definitions of what autism is, and also what caused an autistic developmental pattern in children have been hotly contested ever since” (p. 1). Since the designation of autism as a separate disorder by both Kanner and Asperger, there have continued to be changes in the way the field of psychology views this condition.

The relationship between parenting and autistic symptomatology has been discussed since the work of Kanner. His statements evolved into the concept of the “refrigerator mother,” which was a theory postulating that the development of autism was due to a lack of parental warmth. Psychiatrists John and Lorna Wing, who had children on the spectrum, fought back against this stereotype and shifted focus to the clinical, educational, and social implications of autism (Langan, 2011). Lorna Wing, who went on to become a leader in the field of autism, specifically discussed the discrimination experienced by parents of autistic children and the resultant psychological toll of being blamed for their child’s impairment (Langan, 2011).

Following the influences of the Wings, parental factors were no longer considered to be the cause of autism. Subsequently, researchers began investigating other potential

causes of autistic “deficits” and searching for a cure (Evans, 2013). The beginning of the 1990s brought about a boom in exposure of both individuals and families experiencing autism (e.g., through television, movies, internet articles, memoirs; Langan, 2011). This combination of efforts by some parents to cure autism and the increase in the public’s awareness of the disorder led to the dissemination of misleading information, such as the unfounded claim that immunizations cause autism. One of the original proponents of the well-known vaccination theory was Andrew Wakefield whose article entitled “MMR vaccination and autism” first circulated the idea that the measles, mumps, and rubella vaccination contributed to the development of autism (Taylor et al., 1999). This theory was quickly rebutted by other professionals in the field, including many of Wakefield’s coauthors, and in 2010, the publishing journal (*Lancet*) decided to fully retract the article (Rao & Andrade, 2011). Another supporter of this theory was American actor Jenny McCarthy (Langan, 2011). McCarthy’s statements contributed to many parents of autistic children losing trust in medical professionals, which led to further controversy and tension in the world of autism.

Recently, this mindset (that individuals with autism need to be cured) has led to disagreements between autistic advocates and parent groups, since many autistics see their diagnosis as a difference (rather than a deficit) and an integral feature of their identity (Kapp et al., 2013). This demonstrates the importance of considering all perspectives in the conceptualization of autism and remembering that autistic individuals are not a monolith. It is important to note that at no recorded point in the history of autism have autistic experiences driven conceptualization; instead, the input of

psychiatrists, psychologists, and caregivers has been at the forefront of research and treatment.

In summary, theories regarding the etiology of autism have suggested that autism was a result of poor parenting, a form of schizophrenia, or a result of routine vaccinations; all of these theories have since been refuted and discredited (Wolff, 2004). While newer and more current theories of autism have aspired to be more evidence-based, many of these approaches still do not speak to the experiences of all autistic individuals and have limited explanatory power in terms of treatment outcomes. For instance, researchers in the field of psychology have focused mostly on how to reduce symptoms or cure autistic individuals (Gernsbacher et al., 2006), and few studies have been conducted with adults, as autism was initially assumed to be a disorder of childhood (Howlin & Magiati, 2017). It is vital to consider which conceptualizations of autism are outdated and in need of further investigation.

A Deficit-Based Approach to Autism

Much of the current understanding of autism is based within the framework of the medical model's approach to diagnosis and treatment (Kapp et al., 2013). The medical model in general (and when specifically applied to autism) classifies individuals into a dichotomy (i.e., healthy or sick) and tends to encourage negative stereotypes about individuals who are "sick" (Bottema-Beutel et al., 2021). This approach's processes and diagnostic categories are empirically supported and embedded in classification and categorization, since someone needs a diagnosis to receive services through an insurance provider. An assumption inherent within the medical model is that autism can be diagnosed in a reliable and timely manner, so that individuals who meet the criteria are

able to receive appropriate care. There are several reasons to doubt this assumption.

Mandall et al. (2007) discuss several of the various factors that may contribute to a delay in care:

...diagnosis is often delayed until children are of school age. This delay may be due to inadequate screening practices, pediatricians' slow response to parental concerns, the low sensitivity of screening instruments for autism, and a general lack of awareness of symptoms. [. . .] Symptoms common to autism, such as delayed speech, poor response to others and behavioral difficulties, can lead to misdiagnosis of language impairment or Attention Deficit/ Hyperactivity Disorder (ADHD). In older children, the presence of repetitive behaviors may steer clinicians toward a diagnosis of obsessive-compulsive disorder (OCD), and non-compliance related to resistance to change may lead clinicians to diagnose oppositional defiant disorder. (p. 1795)

In the medical model, individuals have to work to receive the diagnosis to receive care, even if those on the autism spectrum may disagree with elements of their diagnosis or not agree that their lived experiences fit with the current *DSM-5* categorization. In addition to issues with appropriate/timely diagnosis, the medical model frames autism in terms of deficits, weaknesses, and deviations from “normality” (Campbell, 2008).

Neurobiological Findings

The field of neurobiology focuses on investigating biological mechanisms and similarities in autistic individuals. Neurobiological research acknowledges that there are many distinctions (e.g., structure, connectivity) between autistic and non-autistic brains (Verhoeff, 2015). Although neurobiology is a relatively new addition to literature on

autism, there is a good deal of breadth among topics. Empirical research in this area spans a multitude of foci, including anatomy (e.g., specific brain regions), genetic differences, pathogenic influences, and other external factors (DiCicco-Bloom et al., 2006). These findings demonstrate that autism is a complex and heterogeneous neurobiological condition, which supports the need to conceptualize autism in terms of true differences rather than simply assuming deviation from the norm. The intentions of this research are centered around the connection of autistic features to biological mechanisms (Ecker, 2017), determination of biological mechanisms specific to autism (Freitag & Konrad, 2014), the improvement of procedures to support faster diagnosis and access to treatment (Pardo & Eberhart, 2007), and the development of individualized treatments (Abrahams & Geschwind, 2008; Betancur, 2011; Ring et al., 2008).

Studies focusing on the neuroanatomy of autism involve a variety of methods including imaging (e.g., fMRI), post-mortem examination, and animal models. Findings within this subfield suggest that autistic individuals have reduced head size at birth (Courchesne, 2004; Pardo & Eberhart, 2007), enlarged brain volume in the first two years of life (Courchesne, 2004; Hazlett et al., 2005; Pardo & Eberhart, 2007), disruption of white matter tracts and disconnection between brain regions (Courchesne et al., 2005; Courchesne et al., 2011; Pardo & Eberhart, 2007), and fewer Purkinje cells in the cerebellum (Allen et al., 2008). Data from post-mortem studies also support larger than average head sizes in autistic individuals and decreased numbers of Purkinje cells (DiCicco-Bloom et al., 2006). Other studies suggest that differences observed in neuronal and cortical organization, specifically in the cerebellum, cerebral cortex, and other subcortical structures, are related to autism. In addition to investigations of the

neuroanatomy of autistic individuals, some researchers have attempted to recreate the neurobiological features of autism using animal models (Rindald et al., 2008). This specific approach is still being developed as currently no single animal model captures all the features of autism (DiCicco-Bloom et al., 2006). Despite this, findings from this subset of neurobiological research suggest that features of autism may be partially attributed to such structural differences present from birth.

In addition to neuroanatomy, research focusing on the relationship between genes and autism has contributed a great deal to the understanding of the biological mechanisms present in this condition. Specifically, investigation into genetic mechanisms suggests that autism is highly heritable (Pardo & Eberhart, 2007). However, no single gene has been shown to account for more than 1% of autism cases (Parellada et al., 2014), and genetic data continues to support the idea that autism is a heterogeneous condition (Abrahams & Geschwind, 2008; Betaneur, 2011; Ring et al., 2008). As such, the major focus of this genetics research has been on searching for rare genetic mutations that coincide with autism (Willsey & State, 2015) and exploring the role of rare and de-novo variants via large scale/multi-site studies (Freitag & Konrad, 2014). This approach aims to identify “risk” variants and describe involved pathways in the development of autism.

Although autism is considered highly heritable, the role of environmental factors has also been considered in the neurobiological literature. For instance, Parellada et al. (2014) discuss the potential role of prenatal exposure to teratogenic influences (e.g., drugs, viruses, toxins) during critical developmental periods in the development of autism. Other studies have explored factors such as co-occurring autoimmune conditions

(Parellada et al., 2014), as some studies suggest that up to 60% of autistic individuals also have immune system dysfunction (Korvatska et al., 2002; Licinio et al., 2002; Torrente et al., 2002). Others have explored the impact of various maternal factors on the development of autism, such as maternal autoimmune disease (Pardo & Eberhart, 2007) or maternal infection during gestation (DiCicco-Bloom et al., 2006).

Despite investigations of the neurobiological underpinnings of autism spanning a range of topics, there have been several findings consistently replicated across the literature. Early brain overgrowth, most notably in the frontal lobe and white matter, has been observed in several studies (Courchesne, 2004; Hazlett et al., 2005; Pardo & Eberhart, 2007; Parellada et al., 2014). These differences in brain development appear to occur in the first few years of life and are followed by a slowing in growth (Courchesne et al., 2011; Donovan & Basson, 2017). Furthermore, some studies suggest that the structures in which atypicalities are seen (frontal lobe, cerebellum, limbic structures) are involved in the mechanisms behind features associated with autism, such as social skills, communication, and motor functioning (Courchesne, 2004; Courchesne et al., 2004; Courchesne & Pierce, 2005; Schumann et al., 2004). Differences in structures within the frontal lobes of autistic individuals is another consistently replicated finding within the field of neurobiology. The frontal lobe is a section of the human brain typically associated with executive functioning (e.g., planning, organization, inhibition), attention, language, social and emotion processing (Rinaldi et al., 2008). Frontal regions that have been related to autism include the prefrontal cortex, frontotemporal region, and the frontoparietal region (Belmonte & Yurgelun-Todd, 2003; Dichter et al., 2009; Gomot et al., 2008; Rinaldi et al., 2008). Within these regions, studies have investigated the role of

several brain structures such as the medial orbitofrontal and inferior-frontal cortices, the superior temporal sulcus, and the fusiform gyrus (Ecker, 2017). The fusiform gyrus, which is located within the frontotemporal region, was an early focus of these neurobiological investigations due to its association with facial perception (Allen et al., 2008); in autism, the fusiform gyrus may be hypoactivated, leading to struggles with social communication. This hypothesis is described as one of the best replicated findings related to autism (DiCicco-Bloom et al., 2006; Ecker, 2017; Schultz, 2005). Additionally, diagnoses of autism have been known to frequently co-occur with diagnoses of ADHD (APA, 2013), and neurobiological literature occasionally acknowledges this overlap (Markram & Markram, 2010; Purper-Ouakil et al., 2011). Martinez-Morga et al. (2018) state that differences in the cerebral cortex (e.g., arrangement of neurons, pattern of connections), primarily the prefrontal cortex, are present in individuals with both diagnoses; this is thought to explain overlap in attention-related symptoms in these disorders.

In addition to exploring specific structures within the frontal lobe, researchers have also focused on abnormal patterns of activation. Cohen (1994) developed a neural network model of autism based on studies of neuropathology in autistic brains. This model states that autistic brains display differences in connectivity, such as underconnectivity and short range overconnectivity (Geschwind & Levitt, 2007; Philip et al., 2012), although the impact of these findings is still being debated. More specifically, Cohen (1994) proposes that many of the features of autism “such as sociability, attention, multi-tasking and repetitive behaviors, should be re-interpreted in the light of a hyper-functional prefrontal cortex” (p. 1). For instance, Cohen (1994) suggests that observed

patterns of both hyper- and hypoactivation in various brain regions in autistic individuals would lead to an “overemphasis on specific details” (p. 362). Others suggest that these differences in connectivity affect the brain’s ability to react to changing demands (Parellada et al., 2014).

Integration between regions of the brain may also play a role in these mechanisms. For instance, some researchers suggest that the features of autism may be related to “a reduction in the integration of specialized local neural networks in the brain” (Brock et al., 2002, p. 209). This reduced integration is hypothesized to impact an autistic individual’s ability to generalize and extend learned experiences, which is explained by McClelland (2000) as a hyperspecificity. This phenomenon is explored further by Markram and Markram (2010) in their Intense World Theory. This proposed theory suggests that autistic’s differences in attention and processing are the result of both hyperreactivity and hyperplasticity of neuro-circuits. Researchers hypothesize that these neurobiological mechanisms may result in “hyper-focusing on fragments of the sensory world with exaggerated and persistent attention” (p. 10). Gomot et al. (2008) examined this theory by looking at imaging findings collected via fMRI of 12 autistic children. They found “unusual activation of the inferior parietal and prefrontal regions” in these children’s brains, which they suggest “might contribute to people with ASC overfocusing on specific events when attention is actively directed towards the stimuli” (p. 2486). Further, Rinaldi et al. (2008) propose these patterns of activation, specifically in the prefrontal cortex, have an impact on attention, social functioning, and other areas, such as “multi-tasking and repetitive behaviors” (p. 1). Due to the proposed widespread impact of

these activation patterns, this theory demonstrates the importance of considering neurobiological differences when conceptualizing autistic behavior.

Despite the replication of several major findings related to the neurobiology of autism, there is some disagreement between researchers on how to approach the topic. Herbert (2005) discusses how some neurobiological researchers focus heavily on potential and contributory genetic influences, while others take a systemic approach. Additionally, many studies have been limited due to small sample sizes, the inclusion of co-occurring conditions (e.g., epilepsy and intellectual disability), and potentially biased methods of data quantification (DiCicco-Bloom et al., 2006; Palmen & van Engeland, 2004). Finally, researchers consistently refer to the heterogeneous presentation of autism, which further complicates the determination of a neurobiological mechanism (Abrahams & Geschwind, 2008; Betancur, 2011; Ring et al., 2008). Wylie et al. (2020) states that “understanding the neurobiology of autism spectrum disorder (ASD) remains a formidable challenge” (p. 2765).

Although neuroimaging research has contributed to knowledge about the biological mechanisms present in the autistic brain, it is also important to note that most findings are framed by neurotypical researchers and from a deficit-based approach. For instance, in their overview of the neurobiology of autism, Pardo and Eberhart (2007) describe the autism spectrum as “devastating conditions in the broad range developmental abnormalities known as ‘pervasive developmental disorders’” (p. 434) and discuss how an understanding of neurobiology may assist in the prevention and/or cure of autism. Unfortunately, this characterization of autism is prevalent throughout this body of research (Courchesne, 2002; DiCicco-Bloom et al., 2006; Ecker, 2017; Freitag & Konrad,

2014). Verhoeff (2015) identifies two major issues that exist within this current literature base. First, most of the current neurobiological research on autism neglects the impact of autism on aspects of daily functioning, and instead focuses on prevention or curing symptoms of autism. The second issue identified by Verhoeff (2015) is the continued dismissal of the autistic perspective and neurodiversity movement, which strives to convey the concept that autism is “not a disease to be cured” (p. 443). These issues illustrate that neurobiological research on autism requires further examination to fully capture the lived experience, similar to other content areas contributing to the understanding of this condition.

Neurocognitive Theories of Autism

Theories of cognition in autism are another illustration of the autistic perspective has been mostly excluded as the research literature expands. Three major neurocognitive theories of autism have emerged from the influence of the medical model: Theory of Mind (Baron-Cohen et al., 1985; Frith & Happé, 1999), executive dysfunction (Ozonoff et al., 1991) and Weak Central Coherence (Frith, 2003; Frith & Happé, 1995). It is important to note that these three theories are the most prominently researched and discussed in the autism literature, although there are many other theories related to the conceptualization of autism (Pellicano et al., 2006; Rajendran & Mitchell, 2007).

Vermeulen (2012) identifies these perspectives as “neuro-cognitive explanations of autism...that are now recognized worldwide” (p. 19). These theories are focused on identifying core features of cognition in autism to understand accompanying behaviors (McGeer, 2004).

The theory that appears most often in the literature when discussing cognition in autism is theory of mind (ToM; Fakhoury, 2015). Arguably, research on ToM has dominated the discussions of cognition in autism for decades (Baron-Cohen et al., 1985; Baron-Cohen et al., 1994; Fakhoury, 2015; Yirmiya et al., 1998). This theory has also received significant criticism from autistic advocates (Cromar, 2020; Yergeau, 2013). ToM is defined as the ability to identify and interpret the mental states (e.g., beliefs, intentions, emotions) of oneself and others (Arnaud, 2020; Brewer et al., 2017; Fakhoury, 2015; Perner et al., 1989). According to this theory, deficits in ToM are more common among autistic individuals, suggesting that individuals on the spectrum are more likely than non-autistic individuals to struggle with empathy and perspective taking (Vermeulen, 2012). More specifically, some proponents of ToM argue that individuals on the spectrum are more easily able to understand logic but struggle with empathy (Vermeulen, 2012). Older studies, such as one conducted by Perner et al. (1989), reported that autistic children had “profound difficulty” with understanding mental states when compared to controls on a false belief task (p. 689). ToM is thought to be separate from intellectual functioning, and thus deficits in ToM would only negatively impact social interactions (Brewer et al., 2017).

Another popular cognitive theory of autism is the executive dysfunction theory. Executive functioning refers to goal-directed behavior, planning, and cognitive flexibility in response to transitions or change in the environment (Booth et al., 2003; Trenton & Noelle, 2015). As it relates to autism, the theory of executive dysfunction states that widespread deficits in executive functioning led to the various features of autism (Kenworthy et al., 2005, Vermeulen, 2012). The final of the three prominent theories of

autism is the weak central coherence (WCC) theory. This theory hypothesizes that autistic individuals have trouble seeing the “big picture,” connecting ideas, and processing information globally (Loth et al., 2008; Vermeulen, 2012) and is referenced in some of the current neurobiological literature on autism related to hyperactivation of certain brain regions (Cohen, 1994; Herbert, 2005). WCC suggests that the core differences displayed in autism are due to a lack of ability to integrate detail (Burnette et al., 2005). In addition to being widely recognized, these three theories are likely complementary in their approach and focus almost exclusively on deficits in autism (Loth et al., 2008; Pellicano et al., 2006).

It is noteworthy that these three cognitive theories of autism share several of the same criticisms. First, these theories attempt to explain autism in terms of a “single primary deficit” (Pellicano et al., 2006), which has been disputed by many (Booth et al., 2003; Burnette et al., 2005; Vermeulen, 2012). Second, the foundations of these approaches are based in framing autism through the lens of impairment or deficit, and there is little discussion of any advantages or strengths (Booth et al., 2003). Finally, most of the data collected to establish and support these theories were gathered by non-autistic researchers (Booth et al., 2003; Brewer et al., 2017; Burnette et al., 2005; Loth et al., 2008; Perner et al., 1989). Milton (2018) argues that the voices of those with autism are the most critical and the least utilized in current psychological research. He further suggests that this results in a burden falling on autistic individuals to conform to a society that was not built for them (Bagatell, 2010), with few efforts being made by neurotypical individuals to consider autistic perspectives (den Houting, 2019).

Treatment Approaches

In addition to understanding the underlying mechanisms present in autism, it is vital to understand the efficacy of treatment practices with this population. Similar to research on the neurobiological and cognitive features of autism, literature on treatment consideration and outcomes are in need of expansion to better understand and support the autistic lived experience. This understanding is important, as autistic individuals have frequent contact with the mental health system (Cromar, 2020; Mattila et al., 2010; Weston et al., 2016; Woods et al., 2013). As children, they may be brought by their parents to treatment. As adults, they may continue to seek treatment, as research shows that autistic individuals have high rates of mood and anxiety disorders (Blainey et al., 2017; Cooper et al., 2017; Lake et al., 2014).

Some studies estimate that over 50% of autistic individuals who are considered “high-functioning” present with symptoms of a comorbid disorder (Cromar, 2020). Buck et al. (2014) reported that many co-occurring diagnoses have been identified among autistic individuals, including anxiety, OCD, depression, intellectual disability, psychiatric disorders, and ADHD. Some co-occurring diagnoses, such as mood disorders, are thought of as secondary conditions meaning they are causally related to the primary diagnosis of autism (Chamak et al., 2008). For example, differences in information processing are considered a primary impairment in autism and could lead to secondary difficulties such as depressed mood, communication problems, or social struggles. Treatment models tend to focus on the treatment of anxiety in autistic individuals (Weston et al., 2016), and one study examining mental health in autistic children found that nearly 40% experienced anxiety (Murphy et al., 2017). Additionally, there are higher

rates of suicidal ideation and acts in this population (Kirby et al., 2019), and autistic individuals may struggle with social interactions and activities of daily living (Lake et al., 2014). However, one should not assume that these difficulties are necessarily caused by their autism, which is an assumption consistent with the medical model and the framing of autism as a deficit. A competing explanation could be that autistic individuals are struggling to cope in a world that was not built for them. A thorough examination of treatment outcomes should include the voices and perspectives of autistic individuals to see how they frame their difficulties, and what they hope to achieve in treatment.

When reviewing mental health outcomes and treatment associated with autism, it is vital to include a discussion of such topics in autistic adults. Including the voices of autistic adults could clarify whether treatment is sought to “cure” or extinguish characteristics of their autism or to cope with challenges they face in relationships with neurotypical individuals and neurotypical systems. There has been a recent call for research with autistic adults in the research community (Gillespie-Lynch et al., 2017; Howlin, 2013; Howlin & Magiati, 2017; Punshon et al., 2009). Although most autism research has been conducted with children, prevalence rates of autism in adults are similar (Howlin, 2013). The *DSM-5* states that approximately 1% of the population is autistic (APA, 2013) with similar prevalence rates in children and adults. Additionally, another study found that 63.1% of autistic research participants were between the ages of two and eight with fewer than 2% over the age of 20 (Edwards et al., 2012). The reason for this skew in research focus is unclear but likely attributed to autism being thought of as a childhood diagnosis (Gernhardt & Lainer, 2011; Howlin, 2008). Furthermore, most of the research conducted with autistic adults has focused on observed negative

outcomes. For instance, Howlin (2013) found evidence for several negative outcomes for autistic adults related to health, education, occupation, and social services. It is important to note that many of these outcomes are collected objectively (using measures normed on a sample of the general population) and gather information related to autistic adults' employment status, independence, and social participation. Although one study showed more positive outcomes on self-report measures of functioning, objective measures of social outcomes for autistic adults were still poorer than those of their neurotypical peers (Howlin & Magiati, 2017). Subjective factors were typically measured using self-report measures and included life satisfaction, physical and mental health, living conditions, and relationships, whereas the methods for objective measurement typically involve observations of autistic individuals (Howlin & Magiati, 2017). Quality of life is another variable typically used as an outcome measure in similar studies (Botha et al., 2020). Overall, this inconsistency in findings across measures of daily functioning supports the need to explore both objective and subjective measures of functioning in autism.

Including the perspectives of autistic adults will also clarify the trajectory of autism throughout the lifespan. Currently, little is known about if and how autism changes over time, affects mental health, and impacts or is impacted by mortality and aging (Howlin & Magiati, 2017). Although many questions remain in the research surrounding autistic adults, early research has begun to include the perspectives of this population. Punshon et al. (2009) investigated the experiences of 10 autistic adults, recruited through local services, who were diagnosed, via structured interviews, in adulthood. Researchers developed open-ended interview questions using a pilot group pre-study that were centered around the experience of diagnosis (e.g., "How did you feel

in the weeks after your diagnosis?"; p. 282). The overwhelming message from these adults was a feeling of being misunderstood before their diagnosis. Importantly, adults in this sample recognized both negative and positive aspects of the diagnostic experience and "did support the view that reactions to diagnosis are often complex, with a number of possible contributing factors" (p. 280).

Treatment Considerations. Similar to the multitude of considerations when conceptualizing and/or diagnosing autism, there are many treatment approaches to contemplate when working with autistic individuals (Lake et al., 2014). Pharmacological interventions are often used to manage co-occurring diagnoses or behaviors associated with autism. The most common medications cited in the current literature are stimulants, antidepressants, and neuroleptics (Martin et al., 1999; Rosenberg et al., 2010). In a review of mental health services for autistic adults, Lake et al. (2014) reported that many studies focused on treatment outcomes related to functional autonomy, quality of life, social challenges, and challenges accessing services when evaluating the utility of these medications. However, research on psychotropic medication interventions is limited and typically focused on children (Lake et al., 2014). Social skills training is another prevalent treatment with this population as difficulties in social communication are considered a key feature of an autism diagnosis (Corona et al., 2019; Davis et al., 2018; Hong et al., 2019; McVey et al., 2016). Despite this, findings examining the efficacy of social skills training are inconsistent and typically only researched in children (Shuai & Lin, 2020).

In addition to exploring the efficacy of social skills training, there have been many studies focusing on the effectiveness of psychological interventions in supporting

autistic individuals, with the most empirical support for cognitive behavioral therapy (CBT; Cromar, 2020). Indeed, research on CBT with this population demonstrates improvement in mood/anxiety symptoms and social disability, especially among autistic children (Lake et al., 2014; Murphy et al., 2017). Furthermore, CBT appears to be a promising treatment for some autistic individuals, especially those with symptoms of anxiety and/or depression. There are several other psychotherapeutic approaches that show promise in supporting autistic individuals, although they are rarely the focus of research (Spek et al., 2013). Early data on person-centered therapies and autism are promising (Cromar, 2020; Murphy et al., 2017). Cromar (2020) makes several suggestions for the use of person-centered therapy with autistic individuals. These recommendations include focusing on the therapeutic relationship and the formulation of a positive self-identity as vital, while also adjusting expectations around body language (such as eye contact), communication style, sensory input, and boundaries to best suit the needs of the client.

Although most psychotherapy studies focus on the efficacy of CBT in the treatment of autistic individuals, the autism community has expressed many criticisms related to this approach. These criticisms can be echoed across most treatment outcome studies for autism, as there is no clinical consensus or consensus from autistic advocates in terms of what a “good treatment outcome” is (Weston et al., 2016). Other limitations specific to CBT trials include an overreliance on samples of autistic children (Weston et al. 2016) and a lack of comparison to other forms of psychotherapy (James et al., 2015; Storch et al., 2013; Sukhodolsky et al., 2013; Sung et al., 2011). Additionally, CBT represents a problem-solving approach with a collaborative sense of treatment goals, and

it is unknown how often a clinician's sense of treatment goals overlaps with the self-identified goals of individuals on the spectrum, who may not see their autism as something to "change."

Despite some promising research, there is still a need for investigations of treatment efficacy. Additionally, many of the established treatments for working with this population focus on symptoms or struggles, rather than strengths, which could limit treatment acceptability for autistic individuals (Comar, 2019/2020; Vermeulen, 2012; Weston et al., 2016). Furthermore, most treatment strategies do not take the autistic perspective into account (Howlin & Magiati, 2017). For example, the consideration of sensory-seeking behaviors (e.g., stimming) as an adaptive behavior has been identified by autistic adults as an effective coping strategy to self-soothe or allow in the communication of intense emotions (Kapp et al., 2019). The potential benefit to incorporating such strategies into conceptualization and treatment allows treatment providers to focus on the strengths of this population, while supporting the development of positive coping strategies. This lack of further examination limits the field's ability to best support autistic individuals as impactful factors, such as the impact of stigma, are rarely addressed.

The Influence of Social Factors

As demonstrated across multiple domains of the literature (neurobiological, cognitive, treatment), many of the current approaches to understanding and supporting autistic individuals have minimized the importance of outside factors and focused on the idea that differences stem simply from being autistic (Booth et al., 2003; Brewer et al., 2017; Burnette et al., 2005; Loth et al., 2008; Perner et al., 1989). For example, poor

quality of life tends to be assumed in autistic individuals without any consideration of the impact of negative social factors (Botha et al., 2020). Some researchers have begun to discuss the impact of social factors on the autistic experience; this exploration has identified several impactful social factors such as the double empathy problem (Milton, 2012a), environmental goodness-of-fit (Lai & Szatmari, 2019; Leadbitter et al., 2021; Ungar, 2014), stigma (Leadbitter et al., 2021; Perry et al., 2021), and masking or camouflaging (Cage & Troxell-Whitman, 2019; Jorgenson et al., 2020). A consideration of social influences also allows for a multifaceted understanding of autism and the development of autism-specific theory (Woods & Waltz, 2018). These approaches seem to indicate that societal factors have a significant impact on the experience of having autism.

The “double empathy problem” refers to the tendency for both autistics and non-autistics to struggle with understanding each other’s lived experience. This concept explores socialization differences from both the autistic and non-autistic perspective and was originally introduced by Milton (2012a). Milton, an autistic researcher, describes this conflict as occurring when people with different outlooks attempt to communicate and fail, with resultant discomfort experienced by both parties. As it relates to the topic of autism, the double empathy problem often results in stigmatization against autistic differences (e.g., reduced eye contact). Milton (2012a) suggests that when one party (non-autistics) believe their perspective is correct or normal, stigma against the other party occurs. The double empathy problem demonstrates that behaviors associated with autism can be misunderstood within a social context.

Similarly, other studies support the need for consideration of social factors or environmental fit in the context of autism (Lai & Szatmari, 2019; Leadbitter et al., 2021; Ungar, 2014). In fact, Kalisch et al. (2015) argue that socio-environmental factors influence resiliency in all adults. Leadbitter et al. (2021) suggest that researchers should move away from the “normative agenda” (p. 1), which aims to normalize or cure individuals, and integrate considerations of environmental goodness-of-fit into interventions used to support autistic individuals. Similarly, Lai and Szatmari (2019) suggest that research and practice with autism should consider the use of a social-ecological framework, as many of the challenging experiences autistic individuals face stem from poor person-environment fit and inadequate contextual accommodation. This suggests that disability does not come from the individual per se but from the fit between the individual and the larger social context. The authors further suggest that improvement in the “goodness of fit” between autistic individuals and their environments (social and physical) may combat the effects of stigma and result in more positive outcomes (Lai & Szatmari, 2019).

Consideration of the double empathy problem and environmental goodness-of-fit demonstrates how outside social factors (e.g., environment, social interactions) contribute to negative perceptions of autism or stigma. Stigma is defined as “the possession of an attribute that marks persons as disgraced or ‘discreditable,’ marking their identity as ‘spoiled’” (Pearson & Rose, 2021, p. 53). Furthermore, since stigma has an impact on how a person is viewed by others, any negative treatment associated with such views has the potential to impact an individual’s identity. Botha et al. (2020) argue that investigating autistic stigma may contribute to a deepened understanding of mental health

outcomes in autism. The authors frame autistic identity as a “neurominority,” stating that many autistic individuals consider their diagnosis to be a vital part of their identity while experiencing social stress related to resultant stigma. Minority status includes the involvement of several stressors related to stigma, such as discrimination, internalized stigma, and concealment (Botha et al., 2020). Similarly, several studies investigating the intersection of stigma and autism found that autistic individuals consistently report experiences of stigmatization (Botha et al., 2020; Pearson & Rose, 2021; Perry et al., 2021). These findings also suggest that autistic individuals are negatively impacted by stigma, as reports of autism-related stigma was associated with low self-reported wellbeing (Perry et al., 2021). As a result of constant exposures to stigma (Botha et al., 2020), autistic participants reported several coping strategies such as “reframing to more positive understandings of autism, reclamation of language, and using concealment/disclosure strategically” (p. 1). Pearson and Rose (2021) also found that autistic individuals may attempt to avoid stigma through concealment or “masking” and consider it a social strategy.

It is also vital to consider the impact of stigma when treatment approaches based in a deficit-model aim to extinguish behaviors associated with autism (e.g., limited eye contact, self-stimulation). Such an approach may result in camouflaging or “masking” by autistic individuals (Cage & Troxell-Whitman, 2019; Hull et al., 2021; Pearson & Rose, 2021; Perry et al., 2021). Pearson and Rose (2021) explain camouflaging as “the conscious or unconscious suppression of natural autistic responses and adoption of alternatives across a range of domains” (p. 52). Perry et al. (2021) used Social Identity Theory to examine the relationship between camouflaging and stigma in autistic

individuals and described two general reasons for camouflaging: to fit into a non-autistic world and to maintain relationships. Data were collected via an online survey of 223 autistic adults and showed that increased instances of camouflaging were associated with increased instances of autism-related stigma (Perry et al., 2021). Furthermore, camouflaging did not have a mediating effect on the effects of stigma, suggesting that it may not be a beneficial coping strategy. Although camouflaging/masking may have some positive effects (e.g., increased ability to fit in), many autistic persons identify detrimental effects of this practice, such as mental, physical, and emotional exhaustion (Hull et al., 2021; Jorgenson et al., 2020; Perry et al., 2021). Several studies have demonstrated negative mental health outcomes in autistic persons due to masking such as depression, anxiety, stress, and poor wellbeing (Cage & Troxell-Whitman, 2019; Perry et al., 2021). Similarly, Cassidy et al. (2020) found that masking autistic traits was associated with reported struggles to belong and an increased risk for lifetime suicidality based on a cross-sectional comparison of undergraduate students.

Similar to stigma, masking results from a lack of understanding by non-autistics (Milton, 2012a) and incongruence with one's environment (Lai & Szatmari, 2019). Unfortunately, studies on these factors are limited and require further investigation. However, these approaches still provide additional considerations and insights that are useful in understanding and supporting this population and the current data demonstrate the importance of considering social influences on the experience of autism due to their impact on functioning. Furthermore, the integration of these factors with other aspects of autism (e.g., cognition) allows for the development of multi-faceted theories. Integrative theories of autism, such as the theory of monotropism, attempt to address all aspects of

the condition (e.g., cognitive and sensory differences), while considering the impact of social factors and the perspectives of autistic individuals. For instance, Dakin and Frith (2005) suggest that the superior processing of details and weaker processing of global information may be related to differences in social interactions observed in autism, which require a simultaneous focus on details (e.g., body language) and global context (e.g., topic of conversation).

Monotropism. The theory of monotropism suggests that the differences associated with autism have an impact on its various features (e.g., sensory interests, repetitive behaviors, struggles with reciprocal socialization; Milton, 2012b) and affects multiple areas of functioning. Murray et al. (2005) postulate that the differences associated with autism are not deficit-based, but rather the result of an underlying mechanism: monotropism. Monotropism is defined as “the tendency for our interests to pull us in more strongly than most people [...] In a monotropic mind, fewer interests tend to be aroused at any time, and they attract more of our processing resources, making it harder to deal with things outside our current attentional tunnel” (Murray, 2019, p. 45). This theory explores the idea that the brains of autistic individuals are monotropic rather than polytropic, in that monotropic minds tend to focus on information singularly instead of simultaneously. Recently the theory of monotropism is receiving more attention within the research community (Chown et al., 2017; Milton, 2019; Woods & Waltz, 2018).

In fact, Murray et al. (2005) argue that this theory applies to all components of the current diagnostic criteria and provides a more comprehensive view of autism than other theories. The attentional differences seen in monotropic minds can affect language, social interaction, interests, and many other aspects of their daily functioning (Milton, 2012b).

For example, the impact of monotropism on social functioning may present as a lack of empathy or struggles with communication, when in theory an autistic person's brain may struggle to simultaneously process the various aspects of input (e.g., speech, nonverbal gestures, the surrounding environment) that come with socializing. It is also theorized that this localization and concentration of input begins early in language development (Murray et al., 2005), which may contribute to the differences in communication typically associated with autism. Autistic individuals may experience discrepancies in auditory attention (hyperactivation versus hypoactivation), which could affect language acquisition, such as engaging in perseverative speech or minimal verbal communication. Socially, autistic individuals may take longer to keep up with social discourse and its various complexities (e.g., body language, environment, content of conversation). There are also many unwritten rules that need to be focused on simultaneously regarding both language and general socializing, which could be experienced as chaotic or illogical to someone on the autism spectrum.

I think that for many of us diagnosed as being on the spectrum of autism, the demand of having to 'pay attention' to so many things, simultaneously, is a nightmare. We tend to focus upon one thing at a time and this might mean we 'miss' lots of superficial information that gives context to much of life (conversation, expectation, realization). However, when one understands this, it should make relating to us less troublesome. When I am upset I may give out signals that can be misinterpreted as 'difficult.' Most of the difficult behavior, however, seen in autism, is due to fear and discomfort. Learning to recognize this

is the first step to helping us all to develop more appropriate communication systems. (Murray et al., 2005, p. 152)

This quote demonstrates the potential value of integrating multifaceted theories, such as monotropism (Woods & Waltz, 2018), into the field of psychology's approach to understanding autism. The interaction between the features of autism and various social factors (e.g., environment, stigma) clearly has a dramatic impact on the day-to-day life of an autistic individual. Overall, it is clear that further examination of social phenomena allows for a better understanding of autistic strengths and effective support strategies.

Conceptualizing Autism Outside of the Medical Model

Although research on social factors may allow for a more thorough understanding of autism, the fact remains that the vast majority of research is centered around the presence of so-called structural or cognitive deficits (Booth et al., 2003; Dinishak & Akhtar, 2017; Fletcher et al., 2017; Kenny et al., 2017; McGeer, 2004; Pellicano et al., 2014). The medical model or any approach that assumes that features of autism must be remedied through treatment also communicates mostly negative views of autistic individuals (Yergeau, 2013) and an ableist perspective (Bottema-Beutel et al., 2021). An autistic participant stated in Kenny et al. (2016):

Autism can lead to difficult experiences for the person on the spectrum, but it only becomes a disabling condition within the context of an ableist society which does not understand, cares little for or offers limited support to people with autism. (p. 448)

According to the Center for Disability Rights, ableism is defined as “a set of beliefs or practices that devalue and discriminate against people with physical, intellectual, or

psychiatric disabilities and often rests on the assumption that disabled people need to be ‘fixed’ in one form or the other” (Smith, n.d., p. 1). In their article focusing on guidelines for autism researchers, Bottema-Beutel et al. (2021) stress the importance of reflecting upon and identifying ableist tendencies. They specifically focus on the impact of language as ableism is reinforced by cultural norms, speaking, and writing. Some examples include using identity first language (e.g., autistic person) over person first language (e.g., person with autism), switching from deficit-based language (“high functioning” and “low functioning”) to describing specific strengths and weaknesses and switching out the term “symptoms” for characteristics, features, or traits. Furthermore, many advocate for the inclusion of autistic individuals in all aspects of research, such as participatory studies, mentorship, and review (Milton, 2019; Nicolaidis, 2019).

The social model of disability considers conditions such as autism to be a difference (rather than a deficit) and only potentially disabling, while clarifying the differences between impairments and disabilities. Impairment refers to socially valued differences whereas disability refers to environmentally mediated losses of opportunity (Bottema-Beutel et al., 2021). The main difference between the medical model and the social model is how each model defines disability. The deficit-based approach mostly focuses on disability as something that needs to be fixed, while the social model provides more nuance. For instance, many autistics consider autism to be an integral piece of their identity (Kenny et al., 2016) and prefer the use of identity-first language (autistic person) rather than person-first language (person with autism) or consider certain behaviors (such as hyperfocus) to be both disabling and beneficial (Russel et al., 2019). As such, it is important to consider that many of the current diagnostic, research, and treatment

approaches to autism are based in this deficit-based approach (Cromar, 2020). Although the medical model is commonly used and has resulted in an expansion of the understanding of autism, this approach does not allow for a heterogeneous examination of benefits and difficulties in a way that fully captures the autistic experience.

In response to this long-standing approach, the autism community and their allies have been calling for inclusive autism research for decades (Nicolaidis, 2019). Many autistic individuals report feeling dissatisfied with the foci of autism research and would prefer projects to focus on ways to improve day-to-day functioning, rather than understanding the origins of autism (Milton, 2019; Woods & Waltz, 2018). Additionally, there have been few efforts to involve autistic individuals in research overall (e.g., participation and interpretation of findings), and many studies of autism do not include or rely on nuanced theories of autism that consider both strengths and weaknesses, such as the theory of monotropism (Chown et al., 2017). Unfortunately, due to the field's lack of inclusion, there is increasing mistrust of researchers in the autism community and tensions between stakeholder groups (Woods & Waltz, 2018). Milton (2019) argues that this exclusion stems from the idea that autism is a "medicalized set of deficits to be remediated in some way" (p. 1). In addition to the lack of inclusion, there are additional barriers to the inclusion of autistic individuals and perspectives in research. Many of these obstacles (e.g., linguistic or cognitive demands) stem from autism being a heterogeneous condition, meaning that attempts to include autistic individuals may still leave some group members out (Milton, 2019). Regardless, it is imperative that steps are taken towards inclusive autism research.

In addition to needing expansion, most of the current autism research (e.g., neurobiology, cognition, treatment approaches) also demonstrates these issues of exclusion. Across the board, autism is typically framed as a deficit (Booth et al., 2003; Burnette et al., 2005; Pardo & Eberhart, 2007; Pellicano et al., 2006; Vermeulen, 2012), findings typically exclude the lived perspective (Brewer et al., 2017; Burnette et al., 2005; Loth et al., 2008; Perner et al., 1989; Verhoeff, 2015), and strengths are rarely discussed (Booth et al., 2003; Comar, 2019/2020; Vermeulen, 2012; Weston et al., 2016). Further, research on the social factors (e.g., double empathy problem, stigma, masking) demonstrate an impact on the experience of autism but are often not considered in conceptualization or intervention (Jorgenson et al., 2020; Milton, 2012a; Pearson & Rose, 2021; Perry et al., 2021). Despite these obstacles, there are promising implications and suggestions on how to best to incorporate all aspects of the autistic perspective. On one hand, multifaceted theories that resonate with the autistic experience have begun to be circulated. The best example of this is the theory of monotropism, which Woods & Waltz (2018) describe as “the strongest autism theory” as it addresses aspects of cognition and sensory differences in a neutral manner (p. 2). In addition, several researchers have worked to develop inclusive guidelines to inform future autism research. Gowen et al. (2019) aim to “reduce some of the dissatisfaction that members of the autism community feel towards research” through recommendations organized into pre-study considerations, recruitment of participants, study visit considerations, and post-study considerations (p. 1). Some suggestions include introductory research materials, use of multimedia in study recruitment, outlining the study day, and sharing research findings with participants. Similarly, Pellicano and Stears (2011) suggest the use of large-scale surveys and the

incorporation of autistic advisory groups to review research methodologies. These authors also suggest that moving forward researchers must address the knowledge gap between existing perceptions of autism, new science, and research applications. Furthermore, Pellicano and Stears (2011) discuss how many of the current efforts to advance the idea of inclusive autism research are framed within the concept of “neurodiversity.” This concept is referenced across studies aimed at inclusion either directly or indirectly (Bottema-Beutel et al., 2021; Gowen et al., 2019; Milton, 2019; Nicolaidis, 2019; Verhoeff, 2015; Woods & Waltz, 2018) and is built around the understanding of autism as a neurominority.

Neurodiversity

The neurodiversity movement is consistent with the social model of disability in that it encourages a nuanced conversation about strengths and challenges encountered by autistic individuals. Neurodiversity is based on the principle that psychological and biological differences, such as autism, should be viewed as a different but valid way of thinking and perceiving the world, rather than strictly as a diagnosis or disorder (Kapp et al., 2013; Krcek, 2013; Langan, 2011; Milton, 2018; Singer, 1999). den Houting (2019) states that the neurodiversity movement strives for acknowledgement of the natural variation in cognitive mechanisms and the varying degrees of disability associated with autism. A key concept of this movement is that disability is socially constructed (Bagatell, 2010), with a focus on coping strategies rather than a cure. Proponents of this theory do not ignore the disabilities that may accompany the autistic experience, but rather reframe them as resultant of an ableist society. In fact, autistic participants have

reported that one benefit of diagnosis is having access to supportive therapies and services that help them to navigate a complex social world (Kenny et al., 2016).

In addition to bringing about a change in perspective, the neurodiversity movement has brought a more concerted effort to make the voices of those on the autism spectrum the center of conversation about autism (den Houting, 2019; Milton, 2018; Nuwer, 2020). Such subjective approaches allow for a more comprehensive understanding of autism and make way for conceptualization outside of the dichotomy of the medical model (Grove et al., 2018). There are many other benefits to centering the voices of autistic adults such as shedding light on the experience of autism in adulthood (Grove et al., 2018), focusing on lived experiences rather than clinician observations (Kapp et al., 2013), and understanding the potential strengths and weaknesses of the autistic experience (Russell et al., 2019). Additionally, one must acknowledge the presence of different perspectives within the autism community (Fletcher-Watson et al., 2017). For instance, differences of opinion may exist based on the intersectionality of autism with race (Jones & Mandell, 2020; Mandell et al., 2009; Onaiwu, 2020), gender (Cooper, Smith et al., 2018; Lai et al., 2015; Mandy & Lai, 2017; Warrier et al., 2020), and cognitive differences (Fletcher-Watson et al., 2017; Totsika et al., 2010), with limited research in these areas and far more co-occurring identities to consider. As stated by one autistic research participant, “this research must be done in order to improve the lives of autistics to make them empowered and happy, and not in order to stigmatize them” (Fletcher-Watson et al., 2017, p. 70).

Such studies are vital to our understanding of autism, as most of the conclusions made about this population are by those who “lack the lived experience” (Gillespie-

Lynch et al., 2017, p. 1). Despite a general lack of the autistic perspective in the current literature, researchers interested in the autistic perspective have identified three major themes of the autistic experience: feelings of difference, social implications, and strengths. In a survey of autistic adults, family members, and lay individuals on the neurodiversity movement, Kapp et al. (2013) found that individuals who identify as autistic and are aware of the neurodiversity movement are likely to understand their experiences as differences, rather than as deficits. A related study interviewed nine autistic college students about their perceptions of autism and the societal reaction to this diagnosis and found that “feelings of difference” was a common theme among participants (Jones et al., 2013). Results also demonstrated that autistic adults have an awareness of the complexities present in interpersonal interactions, a desire to fit in, and experiences of being regarded as different. Notably, the results of this study were analyzed secondarily by an “expert author” who was autistic. Jones et al. (2013) stated that the inclusion of this expert “specifically aided in the interpretation of participant accounts,” which further supports the utility of incorporating the autistic perspective into research methodology (p. 135).

Kenny et al. (2016) reported similar findings after investigating how autism is perceived from the individual, parent/friend, and professional perspective after surveying 3470 UK residents. In this study, autistic participants discussed several aspects of the idea that autism should be considered as a difference rather than a disorder. Specifically, most autistic participants, family, and friends reported preferring usage of the term “autistic” versus “autism spectrum disorder.” This contrasted with the perceptions of professionals who reported to prefer using the term “autism spectrum disorder” when

referring to this population. Some autistic participants further stated that autism comes with a different worldview and that current societal standards contribute to disability more so than their autism itself (Kenny et al., 2016). The consensus of this exploratory literature is clear: that autistics feel misunderstood by outsiders (McGeer, 2004) and stresses that a diagnosis of autism does not necessarily mean deficit, while acknowledging that being autistic in a neurotypical world may result in accompanying disability. Additionally, in Milton and Sims's (2016) discussion of how autistic adults construct a sense of well-being and belonging, they found that the effort it takes to normalize behaviors is "limiting and likely counterproductive" (para. 3). As discussed previously, such behaviors (also referred to as "masking") can have a significant impact on the mental health of autistic individuals (Milton, 2018; Jorgenson et al., 2020; Perry et al., 2021). This suggests that autistic individuals experience distress as a result of trying to hide their differences rather than from the differences themselves.

In fact, research has found that many of the so-called cognitive deficits associated with autism may have unexamined benefits for individuals on the spectrum (Grove et al., 2018; Russell et al., 2019). Gernsbacher et al. (2006) reviewed the current literature on cognitive science and demonstrated autistic strengths in the areas of perception, reasoning, and comprehension. The authors demonstrate that autism is associated with cognitive strengths such as visuospatial reasoning abilities, recognition memory, and sentence comprehension. Russell et al. (2019) also describes how there is evidence of strengths in autism both in neuropsychological data and personal accounts. Similarly, Dawson et al. (2007) aimed to challenge the assumption that most autistic individuals are cognitively impaired; initially, they found statistically significant differences in scores

after comparing autistic children and adults' scores to non-autistic controls on traditional and nonverbal measures of intelligence. However, when comparing scores across the two measures of IQ, individuals on the spectrum performed significantly better when a nonverbal measure of intelligence was chosen; in fact, individuals on the spectrum scored in the average range when their intelligence was measured nonverbally. Thus, the so-called cognitive deficits assumed to be present among individuals on the spectrum could be an artifact of how intelligence tests often rely on verbal measures and methods, suggesting that cognitive abilities are underestimated in autistics (Dawson et al., 2007). Furthermore, Alvares et al. (2020) examined the relationship between cognitive and adaptive functioning in one of the largest studies of its kind ($n = 2225$) and found only a weak association between IQ and adaptive functioning. This further supports the idea that cognitive abilities in autistic individuals are more complex and variable than previously assumed.

In a study investigating what researchers can learn about autism from autistics, Chamak et al. (2008) found that participants tended to describe their difficulties as a result of the secondary features of autism, such as mental health outcomes, rather than attributed to the primary features of autism (e.g., restricted interests and repetitive behaviors, social struggles, communication difficulties). In fact, recent evidence suggests that such primary features may have positive effects for autistics (Grove et al., 2018). For instance, sensory sensitivities were described by autistic individuals as (at times) contributing to high levels of distress, but also as a source of pleasure in other contexts. Furthermore, Grove et al. (2018) discuss how the presence of special interests, considered to be a defining characteristic of autism, are typically viewed positively by autistics and

had no impact on a measure of psychological wellbeing. Another feature considered to be a primary feature of autism is self-stimulation, typically referred to as “stimming.”

Despite many current treatments of autism making efforts to extinguish this practice, stimming can also be viewed as a coping mechanism that helps with the management of sensory overload, complicated emotions, and “noisy thoughts” (Kapp et al., 2019).

Considerations proposed by the perspectives of autistic individuals may also benefit parents or loved ones who are neurotypical, who may harbor negative, stigmatizing views of traits, or who simply have a different perspective (Fletcher-Watson et al., 2020). Furthermore, the perspectives of autistic individuals could inform how clinicians conceptualize and treat individuals on the autism spectrum (Chamak et al., 2008). These conclusions are echoed by Bradley and Caldwell (2013) who emphasize the need to give up the conventional ways of thinking and allow autistic individuals to show us how they view the world. There are also many research and real-world benefits when the neurodiversity perspective is considered. Doyle (2020) argues that neurodivergent individuals bring both strengths and weaknesses into the workforce. Autistic individuals are more likely to choose and succeed in the fields of mathematics, information technology, and natural sciences, and can also display enhanced abilities in the areas of mathematics, music, visual perception, auditory capacity, and olfactory sensitivity (Wright et al., 2020). In fact, Greta Thunberg, a world-renowned climate activist, credits much of her success to her identity as autistic, describing her identity as a “superpower” (Gambacurta, 2020).

Although the neurodiversity movement is still in its early stages, the efforts of this movement have led to the development of important and inclusive theories of autism

(Murray et al., 2005; Woods & Waltz, 2018), development of strengths-based treatments (Cooper, Loades et al., 2017), and a movement away from therapies geared towards “normalization” (Blainey et al., 2017; Hearst, 2014). However, in the current societal structure, the burden still ends up falling on neurodivergent individuals to conform to a society that was not built for them (Cromar, 2020; Milton, 2018). As such, it is vital for the field of psychology to examine how society defines normal, appropriate, and challenging behaviors through the integration of neurodiversity into psychological research and clinical practice. For instance, self-stimulation (stimming) has been identified by autistic adults as a positive coping strategy; however, many treatments work to extinguish this behavior as it is considered atypical (Kapp et al., 2019). The integration of neurodiversity into clinical practice could involve adjusting current treatment models based on the feedback of autistic individuals. Furthermore, there is evidence in the current body of research that suggests centering the voices of autistic individuals benefits the autism community and society as a whole. Woods and Waltz (2018) state that, “failure to recognize the strength of autistic perspectives, on the other hand, holds back progress and increases the chance of poor-quality research” (p. 5). This integration would allow autistic individuals to advocate for their needs based on their lived experiences, thus informing the focus of future research efforts.

Early efforts to include the autistic perspective, such as the inclusion of autistic researchers, have demonstrated the benefits of this integration and offered valuable insights. For instance, differences in attention are repeatedly identified, especially the tendency to hyperfocus (Milton, 2012b; Rowland, 2020). Murray (2019) describes hyperfocus as potentially being a “huge asset” for autistics in many areas such as science,

math, art, and technology (p. 47). This behavior may allow autistic individuals to develop complex knowledge of an area of interest, finish tasks more quickly, and may provide a sense of self-efficacy and contentment. The presence and impact of hyperfocus is further demonstrated in the concept of monotropism, which suggests that autistics tend to focus on information singularly instead of simultaneously (Murray et al., 2005; Woods & Waltz, 2018). Additionally, Wang et al. (2007) state that “attention is a key factor in determining autistic preference in tasks involving hierarchical stimuli” (p. 3).

Interestingly, mainstream neurobiological and cognitive studies of autism support the presence hyperfocus as well (Casey et al., 1993; Gormot et al., 2008; Isomura, 2015; Markram & Markram, 2010; Rinaldi et al., 2008). Neurobiological findings suggest that observed patterns of hypo- and hyper-activation could result in an overemphasis on specific details (Cohen, 1994) or affect cognitive flexibility in autistic individuals (Parellada et al., 2014). Furthermore, researchers hypothesize that atypical patterns of brain activation present in autistic individuals could lead to an overemphasis on specific events (Gomot et al., 2008) or hyperfocusing on sensory details (Markram & Markram, 2010). Similarly, the Weak Central Coherence theory of autism suggests the presence of hyperfocus on a cognitive level by suggesting that autistic individuals have trouble seeing the “big picture,” connecting ideas, and processing information globally (Loth et al., 2008; Vermeulen, 2012). A further investigation of hyperfocus in autism is not only supported by these multiple domains, but also allows for the sharing of the autistic perspective regarding the impact of this behavior. This integration would produce a deepened knowledge of the autistic experience, while informing future diagnostic and treatment practices.

Hyperfocus

Hyperfocus is an experience that appears to be present across various areas of thought and research on autism (e.g., neurobiology, cognition, social interaction). Rowland (2020) writes that “autism is characterized by perpetual and unrelenting hyperfocus” (p. 2). Hyperfocus is defined as “a state of heightened, intense focus of any duration, which most likely occurs during activities related to one’s school, hobbies, or ‘screen time’” (Hupfeld et al., 2019, p. 192). Similarly, Ashinoff & Abu-Akel (2021) suggest an operationalized definition centered around four features: hyperfocus is initiated by task engagement, is characterized by a state of intense and sustained attention, involves diminished attention outside of the current task involvement, and leads to an improvement in task performance. Hyperfocus has rarely been studied in clinical populations (Ashinoff & Abu-Akel, 2021), although some neurobiological research on autism appears to have identified similar processes (Cohen, 1994; Gormot et al., 2008; Markram & Markram, 2010; Rinaldi et al., 2008). Although rarely researched, hyperfocus has been identified in several psychological conditions in addition to autism, such as schizophrenia and attention-deficit/hyperactivity disorder (ADHD).

This specific gap in the autism literature may also be affected by the lack of individual perspective, the focus on deficits-centered terminology such as perseveration, and/or the tendency of researchers to focus on the extinguishing of behaviors that may allow an autistic person to enter a state of hyperfocus or flow (McDonnell & Milton, 2014). Despite the lack of studies identifying hyperfocus in autism, there is still support that this construct is an important feature of this population. In addition to the term “hyperfocus”, other expressions such as “flow” and “perseveration” appear to address

similar behaviors. Perseveration is defined as a “repetition of actions, verbalization, and interacting with objects in an alternate manner” (Arora, 2012, p. 799). Perseveration is typically associated with the “restricted interests and repetitive behaviors” characteristic of autism and may include action-based (e.g., self-stimulation), object-based (e.g., focus on specific object), or verbal-based behaviors (e.g., echolalia). The perspectives on perseverative interests in autism are mixed. For instance, Arora (2012) characterizes perseveration as a “problematic symptom of autism” (p. 779). Conversely, Koegel et al. (2012) found that incorporating perseverative interests into treatment with autistic individuals may be a strong reinforcer, which could lead to positive outcomes. For instance, these researchers found that autistic children were more likely to both initiate and reciprocate socially when participating in “lunch clubs” that incorporated an aspect of their special or perseverative interests. Generally, research on perseverative interests in this population has struggled to understand the benefits and drawbacks associated with special interests (Maes et al., 2011).

While the term perseveration typically has a negative valence in the clinical literature, “flow” is another term that is similar to hyperfocus but has a positive valence. Flow is a term often associated with the positive psychology movement and coined by Csikszentmihalyi (1990). It refers to being involved in an activity in a way that forms a high-level experience, which can be beneficial to feelings of happiness and wellbeing (McDonnell & Milton, 2014). In order for an individual to enter flow they must have “perceived challenges, or opportunities for action that stretch but do not overmatch existing skills; clear proximal goals and immediate feedback about the progress being made” (Ashinoff & Abu-Akel, 2021, para. 1). There have been several overlaps identified

between the concepts of flow and hyperfocus. Specifically, both constructs involve intense concentration, loss of focus on unrelated stimuli, an interesting or rewarding activity of focus, and improvement in task performance (Ashinoff & Abu-Akel, 2021). McDonnell and Milton (2014) postulate that several features of autism may be attributed to being in a “flow-like state.” One such feature is struggles with social awareness, which the authors suggest may be affected when an autistic individual is in a flow state, as being fully immersed in an activity may inhibit a person’s ability to manage the multiple components involved in interpersonal interaction (e.g., body language, speech, listening). Engagement in repetitive behaviors and specialized interests may be another form of flow. McDonnell & Milton (2014) suggest that flow-like behaviors typically associated with autism may serve as a coping strategy that allows individuals on the spectrum to self-regulate and work towards meaningful experiences.

In addition to the literature on flow and perseveration, instances of hyperfocus in autism have been alluded to in other works as well. In a study of autistic savants (Casey et al., 1993), researchers found that although there was no difference on tasks of visual attention, savants struggled when required to divide their attention between auditory and visual stimuli when compared to controls. In addition, savants had slower reaction times across all study tasks requiring shifting and redirection of attention (Casey et al., 1993). Similarly, Isomura (2015) found that autistic children struggled to detect flower targets when required to disengage from identifying snake targets. Similarly, Rowland (2020) states, “hyperfocus is so intensely single-minded that an autistic person cannot divide attention between two trains of thought” (p. 2).

In schizophrenia, hyperfocus is described as an “abnormally narrow but intense focusing of processing resources” (Luck et al., 2019, p. 991). The hyperfocusing hypothesis of schizophrenia predicts that the presence of this intense focusing is related to the severity of symptoms, in that individuals with more severe symptoms experience more frequent and intense episodes of hyperfocus (Kreither et al., 2017; Luck et al., 2019; Sawaki et al., 2017). This hypothesis has been supported by a variety of studies and methodologies, such as laboratory tasks, behavioral measures of processing, and electrophysiological measures of processing. In fact, Kreither et al. (2017) suggest that this behavior is a fundamental aspect of cognitive differences in people with schizophrenia. Hyperfocus also appears in the research literature on ADHD, which has a high rate of co-occurrence with autism (APA, 2013). Hupfeld et al. (2019) state that “the term ‘hyperfocus’ (HF) has been used to characterize this state of heightened, focused attention that individuals with ADHD frequently report” (p. 191) which echoes the conclusions of earlier research (Brown, 2005; Conner, 1994; Ozel-Kizil et al., 2016).

Recent studies have found that hyperfocus is common among individuals with ADHD traits (Groen et al., 2020; Hupfeld et al., 2019) and were less likely to be present in controls (Ozel-Kizil et al., 2016). Groen et al. (2020) found no significant differences in hyperfocus between a control group and ADHD group but stated that ADHD traits in both groups correlated with the endorsement of hyperfocus. Similarly, in a study developing a self-report measure of hyperfocus (Hupfeld et al., 2019), results demonstrated that individuals who reported higher rates of symptoms consistent with ADHD experienced increased hyperfocus. In a study examining the impact of stimulant medication on the occurrence of hyperfocus, Ozel-Kizil et al. (2016) reported the

endorsement of hyperfocus in both the stimulant and stimulant-naïve ADHD group. Due to the co-occurring nature and diagnostic overlap between ADHD and autism, Ashinoff and Abu-Akel (2021) suggest that hyperfocus may present similarly in autistic individuals, though there is a dearth of research on the autistic experience of hyperfocus.

There are a few commentaries specifically on the experience of hyperfocus, written by psychology professionals who are on the spectrum. One such researcher, Rowland (2020), speaks specifically about the experiences of hyperfocus, stating that it is a “unique and defining characteristic of autism” (p. 2). He connects the experience of hyperfocus to sensory overload and postulates that intense sensory stimuli (e.g., high-pitched noise, touch, seeing too many words on a page) presents a challenge to autistic individuals, who may divert their attention in an attempt to cope (which sometimes results in entering hyperfocus). Rowland (2020) surmised that hyperfocus may be relevant to more than 20 observed autistic traits, most notably passionate pursuit of interests, preference for routine, lack of motivation to socialize, and preference for monologue over dialogue. Rowland (2020) concludes by stating that autistic individuals experience the world through an “intellectual lens,” which may result in extensive knowledge and/or great passion for a narrow area of study. Similar to the research on flow, there is some emerging literature that suggests that autistic individuals experience hyperfocus as an area of advantage (Russell et al., 2019). When interviewed by researchers, nearly all participants mentioned attentional differences in positive terms, with “hyperfocus, attention to detail, and memory” appearing to hold the most benefits from the perspective of autistic individuals (p. 124). According to these participants, self-identified “ability to focus” (which included a subcategory of hyperfocus) allowed them

to work on academics for long periods of time, use their conscientious attention to detail to their advantage at work, and/or find benefit in discussing topics of interest at some length.

Further exploration of the concept of hyperfocus in autistic individuals has far-reaching implications. An exploration of this construct may contribute to an understanding of various features associated with autism, as suggested by the theory of monotropism (Murray et al., 2005). In fact, Ashinoff & Abu-Akel (2021) identify hyperfocus as a “critically important aspect of cognition” (p. 1). Furthermore, other behaviors associated with autism (e.g., perseveration, flow) are similar to hyperfocus, suggesting that such features may be misunderstood or solely framed as deficits. Further investigation of this experience allows for an exploration of its nuances (strengths and weaknesses) as many individuals report positive impacts of their hyperfocus (e.g., long periods of work, attention to detail). Additionally, an exploration of hyperfocus is consistent with the values of the neurodiversity movement as it is autistic researchers and participants continue to identify it as a vital aspect of autism. As such, a further exploration of hyperfocus provides the opportunity to integrate data across disciplines, better understand the impact of this experience, and consider the autistic perspective. Furthermore, this exploration would contribute to general understandings of the condition of autism, which will inform future diagnostic and treatment practices.

Summary and Conclusions

The conceptualization of autism has changed greatly since its infancy. Most of the current theories and treatment approaches are based on a deficit-focused or medical model, with little exploration of strengths and subjective experiences. Furthermore, many of the widely used theories of autism are either stigmatizing or only applicable to some autistic individuals, due to the heterogeneity of the condition. Moving toward a conceptualization that either significantly modifies or operates outside of the medical model is crucial as many autistic individuals still need support related to secondary health concerns (e.g., depression or anxiety) or accompanying disability. Furthermore, current research demonstrates autistic differences in multiple domains such as neurobiology, cognition, and social interaction without an exploration of potential benefits or impacts on daily living. Integrative theories of autism (e.g., monotropism) suggest that the features of autism impact many, if not all, areas of life. In addition, many autistic individuals report benefits to their differences and find the suppression of these features to be stigmatizing. The social model of disability and concept of neurodiversity provide an inclusive framework to further the conceptualization of autism and suggest the importance of considering the autistic perspective in research. Differences in attention are an experience that has been rarely explored in the research literature, but regularly identified by the autistic community. Most discussion is centered around the behavior of hyperfocus, which refers to the act of becoming deeply engrossed in a stimulus with little to no perception of surrounding stimuli. Exploring this behavior through the lens of the autistic perspective will provide insight into how hyperfocus influences and benefits

activities of daily life (e.g., work, school, hobbies) and lead to a deepened understanding of how this behavior relates to autism.

Statement of the Problem

Deepening the understanding of hyperfocus from the perspective of autistic adults is vital. A more nuanced understanding of this construct, how it affects the mental well-being of autistic adults, and the impact it has on daily functioning will inform better conceptualizations of autism. This approach is consistent with the aims of the neurodiversity movement and in contrast to much of the current literature on autism where there is a focus on deficits and observations made by neurotypical individuals. These disorder-based patterns are also present in much of the literature around perseveration and other attentional differences in autism. Recent guidelines for conducting research with the autistic community suggest the use of inclusive language (Bottema-Beutel et al., 2021), collaboration with the autistic community (Pellicano & Stears, 2011), and a focus on research that will improve the daily functioning of this population (Gowen et al., 2019). As such, this study suggests that hyperfocus is a key feature of autism and that the understanding of this behavior from the autistic perspective will allow professionals to better support these individuals clinically. For instance, treatment providers could work with autistic individuals to better understand when they hyperfocus as it may interfere with or benefit areas of daily living. In a similar vein to the writings of Rowland (2020) and Russell et al. (2019), the purpose of this study is to center the voices of autistic individuals while specifically inquiring about their experiences with hyperfocus and any accompanying perceptions of their experience. This

purpose is based on the literature discussed above and the field of psychology's history of dismissing the experiences of autistic individuals. As stated by Murray (2019):

What is true is that our interests pull us in very strongly and persistently, compared with most people. It can be hard to think about anything else when we're particularly invested in a topic, and hard to imagine how little other people might care about it. That can be a huge asset in many fields – intense focus is indispensable in science, maths, technology, music, art and philosophy, among others. Obviously autistic people are not the only ones capable of hyperfocus and persistent interests, but it is a common feature of the autistic psyche, and one that is too often squandered when workplaces and schools are not set up to allow it. (p. 47)

Research Questions and Hypotheses

The research questions investigated in this study included the following: (a) how does the experience of hyperfocus differ between autistic adults, adults with ADHD, and controls; and (b) do autistic individuals describe hyperfocus as beneficial? Two hypotheses will be posed and tested in this study. It is expected that autistic adults in this sample will report experiencing higher degrees of hyperfocus compared to controls and a sample of adults with ADHD (Hypothesis 1). In addition, it is expected that autistic individuals will endorse the presence of benefits related to their experiences of hyperfocus as evidenced by high scores on a newly developed measure (Hypothesis 2). In the event that the newly developed measure cannot be validly scored, Hypothesis 2 will be tested through descriptive statistics, such as more than 50% of the sample Agreeing or Strongly Agreeing with an item related to perceived benefits of hyperfocus.

Chapter II

Methods

Participants

Participants were self-identified autistic adults, self-identified adults with ADHD, and controls. Inclusion criteria included self-identification as autistic, minimum age of 18, as well as the ability to read and understand English as autistic participants will be the only group actively recruited during this study, with other participant data provided by the Hupfeld et al. (2019) study. Autistic participants were obtained through groups and communities dedicated to the autistic experience on social media (e.g., Instagram, Facebook, and Reddit).

Measures

Adult Hyperfocus Questionnaire

The Adult Hyperfocus Questionnaire (Hupfeld et al., 2019) is a self-report measure designed to assess the general tendency for hyperfocus to occur in daily life and the frequency of hyperfocus during school, hobbies, and screen time (Hupfeld et al., 2019). This questionnaire was released to researchers by the authors along with permission for its use in this study (see Appendix A). This measure calculates an overall hyperfocus score based on item totals on five subscales. The items included in the Adult Hyperfocus Questionnaire are designed to measure hyperfocus associated with subscales of disposition (e.g., “Generally, when I am very focused on something or doing something that I find especially rewarding, I can get ‘stuck’ on little details that keep me from finishing other important parts of the task”); school (e.g., “Not realizing how much time has passed since you started your homework or studying”); hobbies (e.g.,

“Completely losing track of time while doing something related to your hobby”); screen time (e.g. “Completely losing track of time while doing the screen time activity”), and the presence of hyperfocus in various scenarios (e.g., “If I get on the internet – especially looking at things like BuzzFeed, Facebook, or Pinterest – I’ll always think that it’s only been a few minutes, but then I’ll see the time and realize I’ve been online for an hour or two”). Participants were instructed to respond to items on a six-point Likert scale ranging from “never” to “daily.” Each subscale score can range from 1 to 72 totaling to a maximum potential hyperfocus score of 288. Lower scores indicate fewer experiences of hyperfocus and higher scores indicate more experiences of hyperfocus. In terms of validity, Hupfeld et al. (2019) reported high correlations between the hyperfocus total score and scenario score. Concerning internal reliability, a Cronbach’s alpha of 0.87-0.99 was reported for measure subscales of the Adult Hyperfocus Questionnaire, which is considered an acceptable Cronbach’s alpha value and indicator of internal reliability (Taber, 2018). In the current research study, a Cronbach’s alpha of 0.98 was obtained for the full measure, also suggesting acceptable internal reliability (Taber, 2018).

Experiences of Hyperfocus Scale

The lead author of this project also developed a measure to gather data on the perception of hyperfocus in autistic adults with the support of the dissertation committee. The Experiences of Hyperfocus Scale was designed to assess experiences of hyperfocus related to associated strengths generally (“My hyperfocus benefits me”) and specifically (“When I hyperfocus, I complete work/assignments/tasks faster”). Participants were instructed to respond to eight items on a five-point Likert-type scale, ranging from “strongly agree” to “strongly disagree.” Each item score can range from 1-5, and total

scores range from 8 to 40. Items one, three, five, and eight were reverse coded. The total score will be calculated as a sum of all individual item scores, and the total score will be interpreted. Lower scores indicate fewer perceived strengths/benefits to hyperfocus, whereas high scores indicate the endorsement of hyperfocus as a strength. This novel scale was constructed based on the study literature and collaboration between authors. Concerning internal reliability, a Cronbach's alpha of 0.74 was obtained, which is considered acceptable by Taber (2018).

Procedure

Autistic participants were recruited through groups for autistic adults on social media sites, including Facebook, Instagram, and Reddit. Data for both control and self-identified ADHD participants were retrieved from the Hupfeld et al. (2019) study for use during data analysis. This study was advertised on these platforms after obtaining permission from group administrators. Interested participants were instructed to click on a link to a Google Forms survey, which provided more information about the study and the informed consent process. Following informed consent, participants were asked to complete the Adult Hyperfocus Questionnaire and the Experiences of Hyperfocus Scale. Participants were also asked several demographic questions, including their gender, age, race/ethnicity, preference for communication, co-diagnosis of ADHD, and occupation. Participants were then thanked for their time and were not compensated. All measures were approved by the Research Ethics Review Board of Immaculata University prior to the start of data collection. Finally, researchers contacted an outside consultant (Dr. Damian Milton) to review study methodology (e.g., Google Forms survey) as an autistic researcher and representative of the autistic community per recent guidelines for

conducting ethical research with this population (Pellicano & Stears, 2011).

Unfortunately, due to scheduling conflicts, Dr. Milton was unable to consult on this project.

Chapter III

Results

Number of Participants

Two hundred fifty-three research subjects completed this study's online survey between July and August 2021. Two hundred forty-seven agreed to participate and self-identified as autistic, resulting in a 98% completion rate. Three potential subjects who agreed to participate were excluded from the study due to age, as they were younger than 18 years old. Three more were excluded from the study due to repeat submissions of the study survey. Following exclusions, the sample included 241 total subjects ($N = 241$). Of the 241 participants, 156 self-identified as autistic and 85 self-identified as autistic with ADHD. Data from these 156 autism group participants and 85 autism/ADHD group participants were used to examine demographic data, scores on the Adult Hyperfocus Questionnaire, and scores on the Experiences of Hyperfocus Scale.

Demographic Data

This study's sample groups included subjects ranging in age from 18 to 77 ($M = 28.20$, $SD = 9.60$). A plurality of participants self-identified as cisgender female (36.30%) and Caucasian/White (77.50%). 35.40% of subjects identified as autistic with ADHD. A further breakdown of participant characteristics is available in Table 1.

Table 1

Sample Demographics

Demographic	<i>n</i>	%
Age		
18-29	158	65.80
30-39	56	23.30
40-49	17	7.10
50-59	5	2.10
60+	4	1.70
Gender		
Cisgender Male	49	20.40
Cisgender Female	87	36.30
Transgender Male	10	4.20
Transgender Female	7	2.90
Nonbinary	21	8.80
Agender/Gender Non-conforming	13	5.40
Gender Neutral/Gender Fluid	4	1.70
Other	38	15.80
Race		
African American/Black	7	2.90
Asian	2	0.80
Biracial/Multiracial	17	7.10
Hispanic	4	1.70
Caucasian/White	186	77.50
Other	22	9.20

Analysis of Data

This dissertation aimed to investigate the experience of hyperfocus in autistic adults. Two hypotheses were posed. It was expected that autistic adults in this sample will report experiencing higher degrees of hyperfocus compared to controls and a sample of adults with ADHD (Hypothesis 1). Data from this study's groups (autism and autism/ADHD) were compared to groups from the Hupfeld et al. (2019) study (ADHD and control) to test this hypothesis.

To test Hypothesis 1, a one-way ANOVA was conducted. Normality statistics revealed skewness and kurtosis within acceptable ranges and results of a Kolmogorov-Smirnov's test ($p > .05$) supported the assumption of normality. The assumption of homogeneity of variance was assessed using Levene's test, $F(3, 609) = 3.12, p = .026$, and indicated a violation of this statistical assumption. However, because analyses of variance are fairly robust to violations of this assumption when a Welch test is performed, the violation did not preclude use of this technique (Lix et al., 1996; Mertler & Reinhart, 2016). As such, a Welch test was conducted to compare group means and to account for the violation of this assumption. Results indicated a significant difference among the groups on AHQ total score, $F(3, 288.60) = 101.84, p < .001$. Games-Howell post-hoc analysis indicated that all possible group-wise comparisons were statistically significant: with the co-occurring autism/ADHD group ($M = 224.48, SD = 38.62$) endorsing the most hyperfocus, followed by the autism group ($M = 202.89, SD = 48.62$), ADHD group ($M = 163.59, SD = 49.34$), and control group ($M = 142.82, SD = 44.80$). These findings support Hypothesis 1 of this study. Further, this data suggests the presence of differences in hyperfocus within the autism group depending on the co-occurrence of self-identified as having ADHD. Finally, this data replicates findings from

the Hupfeld et al., (2019) study that self-identified adults with ADHD endorse more experiences of hyperfocus than controls. Table 2 illustrates mean AHQ total scores and standard deviations for all study groups.

Table 2

AHQ Mean Scores and Standard Deviations Across Groups

Group	<i>N</i>	<i>M</i>	<i>SD</i>
Autism/ADHD	85	224.48	38.62
Autism	156	202.89	48.62
ADHD	162	163.59	49.34
Control	210	142.82	44.80
Total	613	174.92	55.29

Perceptions of Hyperfocus by Group

The second hypothesis of this dissertation was that autistic individuals would endorse the presence of benefits related to their experiences of hyperfocus, as evidenced by high scores on a newly developed measure (EHFS). Preliminary analyses supported this prediction. Specifically, descriptive statistics were obtained for EHFS total score ($M = 32.71$, $SD = 4.41$) across autistic participants ($N = 241$). These findings suggest that participants indicated positive impressions of hyperfocus on all items of this measure, on average. Table 3 displays mean scores for each EHFS item.

To further explore Hypothesis 2, several exploratory analyses were conducted. An independent samples *t*-test was used to examine differences in the perception of hyperfocus between autism groups (autism compared to autism/ADHD). Results demonstrated no significant difference between groups, suggesting that individuals with and without co-occurring diagnoses of ADHD do not vary significantly in their subjective

evaluation of hyperfocus. Further, there was no significant correlation between AHQ scores and EHFS scores, suggesting that the degree to which an autistic individual experiences hyperfocus does not significantly predict their emotional valence of this behavior.

Table 3

EHFS Mean Scores by Item

Item	<i>M</i>	<i>SD</i>
1. My hyperfocus is a weakness.*	3.51	1.03
2. My hyperfocus benefits me.	4.01	0.88
3. My hyperfocus is not useful.*	4.16	0.79
4. When I hyperfocus, I complete more work/assignments/tasks than when I do not hyperfocus.	4.12	1.07
5. When I hyperfocus, I make more mistakes and struggle to focus on small details.*	4.20	0.95
6. When I hyperfocus, I complete work/assignments/tasks faster.	3.77	1.22
7. I know more about my interests because of hyperfocus.	4.70	0.59
8. It is more difficult for me to absorb information when I hyperfocus.*	4.23	0.96

*reverse coded item

Note: All EHFS items used a five-point Likert-type scale, ranging from 1 (“strongly disagree”) to 5 (“strongly agree”).

Chapter IV

Discussion

This dissertation is the first study to explore hyperfocus and perceptions of hyperfocus in an autistic population. Autism is defined by differences in communication, social interaction, and restrictive/repetitive behaviors (APA, 2013). While there is a breadth of research describing behaviors similar to hyperfocus (e.g., perseveration, rigidity), hyperfocus is rarely the focal point of research as applied to autistic adults (Ashinoff & Abu-Akel, 2021). Furthermore, hyperfocus is often framed in the limited extant literature as a negative experience (or a “symptom”) when the emotional valence of the experience of hyperfocus is yet to be determined. The purpose of this study was to center the voices of autistic individuals while inquiring about the presence of hyperfocus, with the hope of informing future clinical conceptualization, research, and interventions.

The first hypothesis explored in this dissertation predicted that autistic adults would report experiencing higher degrees of hyperfocus compared to controls and adults with ADHD. This hypothesis was supported as both autism groups (autism, autism/ADHD) were significantly different from the ADHD and control groups. Specifically, the autism/ADHD group reported the highest amount of hyperfocus followed by the autism, ADHD, and control groups, respectively. These results strongly imply that autistic adults experience the most instances of hyperfocus when compared to another neurodiverse population (ADHD) and neurotypical population (controls). These findings are consistent with research and statements from autistic self-advocates that hyperfocus is a feature of autism (Ashinoff & Abu-Akel, 2021; McDonnell & Milton, 2014; Rowland, 2020). The high frequency of hyperfocus reported in this sample of

autistic adults is meaningful, as much of the limited research on hyperfocus has compared individuals with ADHD to a neurotypical population (Ozel-Kizil et al., 2016) but not autistic individuals (Ashinoff & Abu-Akel, 2021). Notably, the findings of this study also support previous research that individuals with ADHD endorse higher rates of hyperfocus when compared to controls (Hupfeld et al., 2019). Furthermore, the findings of this study are consistent with neurobiological and cognitive research that demonstrates both hypo- and hyper-activated brain patterns (Gomot et al., 2008; Parellada et al., 2014; Wang et al., 2007) and a tendency for local processing and perseveration (Arora, 2012; Loth et al., 2008) as features of autism. Finally, these results are consistent with the theory of monotropism, which postulates that brains of autistic individuals tend to focus on information singularly instead of simultaneously (Murray et al., 2005).

In addition to supporting the theory that hyperfocus is a feature of autism, this dissertation demonstrated a significant difference in the presence of hyperfocus between autistic individuals with and without ADHD. Although this study did not originally aim to have an autism/ADHD participant group, the high percentage of participants with co-occurring ADHD (35.4%) allowed for a more nuanced examination of hyperfocus in this population. One interpretation of this finding is that hyperfocus is a primary feature of both autism and ADHD, as mean AHQ scores in the ADHD group were also significantly different than the control group. Although several studies supported the theory that hyperfocus is common among individuals with ADHD traits, they did not assess for or include subjects with co-occurring conditions (Groen et al., 2020; Hupfeld et al., 2019; Ozel-Kizil et al., 2016). Hupfeld et al. (2019) also demonstrated that individuals who reported higher rates of symptoms consistent with ADHD experienced increased

hyperfocus. Autism is thought to frequently co-occur with ADHD (APA, 2013; Markram & Markram, 2010; Purper-Ouakil et al., 2011) and Martinez-Morga et al. (2018) state that functional differences in the pre-frontal cortex (e.g., the neurological substrates of executive function) are present in both conditions, which certainly has implications for attention.

The second hypothesis of this study theorized that autistic individuals would endorse the presence of benefits related to their experiences of hyperfocus as evidenced by high scores on a newly developed measure (EHFS). To explore this theory researchers examined mean individual and total scores on this measure, compared EHFS scores between autism groups (ADHD/autism and autism), and ran analyses to explore whether a predictive relationship exists between AHQ and EHFS total scores. Analyses did not demonstrate significant differences between study groups or a significant predictive relationship between the degree an individual experiences hyperfocus and their perception of this experience. However, findings for both item and total scores suggest that autistic participants perceive their hyperfocus as beneficial.

Although no other similar scales currently exist, meaning that construct validity could not be established via comparing scores on the newly developed measure to scores on an existing measure of subjective perception of hyperfocus, the descriptive statistics strongly imply that autistic participants are likely to perceive the presence of hyperfocus as beneficial. Furthermore, this finding is consistent with literature suggesting that autistic individuals may benefit from differences in cognition (Doyle, 2020; Gernsbacher et al., 2006; Grove et al., 2018; Russell et al., 2019) and view hyperfocus as a strength (Rowland, 2020; Russell et al., 2019). Overall, these results demonstrate the potential

benefits of hyperfocus and the importance of exploring perceived cognitive strengths in autism research.

Clinical Applications

The potential benefits of hyperfocus are clinically relevant, as most current diagnostic and intervention practices used with autistic individuals focus on the presence of so-called structural or cognitive deficits (Booth et al., 2003, Dinishak & Akhtar, 2017; Fletcher et al., 2017; Kenny et al., 2017; McGeer, 2004; Pellicano et al., 2014), despite objections from the autism community and neurodiversity movement. First, it is vital to consider the presence of hyperfocus when assessing individuals for an autism diagnosis. The results of this study suggest that autistic individuals (with and without ADHD) are more likely to experience hyperfocus when compared to other neurodivergent and neurotypical individuals. This finding supports the consideration of hyperfocus as a diagnostic feature of autism. As such, clinicians should assess for the presence and perhaps degree of hyperfocus when considering a diagnosis of autism or beginning treatment with an autistic individual. It is imperative that clinicians are educated on the concept of hyperfocus and assess for the presence of this experience. Furthermore, this study found significant differences in hyperfocus between autistic individuals with and without co-occurring ADHD, suggesting that individuals with both diagnoses experience hyperfocus to a higher degree. This finding could further aid clinicians in diagnostic conclusions and treatment recommendations between and within these clinical populations.

In addition to considering the role of hyperfocus in diagnosis, clinicians must be comfortable asking clients about this experience, when it occurs, and assessing client

perception. An intentional understanding of this experience allows for in-depth conceptualization and an exploration of benefits and drawbacks. Furthermore, it is important for providers to consider the perception of hyperfocus on other domains of the client's life, such as social interactions and occupation. Although this study focused on the lived experience of autistic individuals, hyperfocus may be perceived differently by family members, significant others, and/or employers. As such, differences in the perception of hyperfocus between autistic clients and others could be another focus of clinical intervention (e.g., family therapy, role-playing conversations). In addition, treating clinicians should consider relative advantages and disadvantages of hyperfocus across settings. For instance, autistic participants in other studies have identified hyperfocus as beneficial in the areas of science, math, art, and technology (Murray, 2019). However, hyperfocus might not be beneficial in other environments, such as social settings, and autistic individuals might feel motivated to hide differences (e.g., masking, which is known to negatively impact the mental health of autistic individuals; Jorgenson et al., 2020; Milton, 2018; Perry et al., 2021). An exploration of these contextual factors in treatment allows for a more nuanced identification of strengths and development of coping strategies.

While supporting autistic clients in the exploration of the nuances of hyperfocus, clinicians should also work to normalize client differences by incorporating the concept of neurodiversity into conceptualization and intervention. It is important to consider that most literature and interventions with the autistic population are based in a deficit model. Conversely, Kapp et al. (2013) found that autistic individuals are likely to consider their experiences as differences rather than deficits. Data from this study supports this

viewpoint. As such, clinicians should work to validate and advocate for their autistic clients. Incorporating the concept of neurodiversity and exploring the benefits of hyperfocus in treatment would support treatment adherence while informing ways to improve the daily living of autistic individuals, which is a common request posited by the neurodiversity movement and autism community (Milton, 2019; Woods & Waltz, 2018).

Limitations

Although the results of this study are positive and clearly indicate both the presence and benefits of hyperfocus in autism, it is appropriate to recognize several limitations. First and foremost, generalizability of this study's findings was limited by several factors. The sample obtained for this research was largely White (77.5%), cisgender female (36.3%), and between the ages of 18 to 29 (65.8%), which limits the ability to generalize findings. Recent studies have demonstrated that there is still a limited understanding of the intersectionality of autism with race (Jones & Mandell, 2020; Mandell et al., 2009; Onaiwu, 2020), gender (Cooper et al., 2018; Lai et al., 2015; Mandy & Lai, 2017; Warrier et al., 2020), and cognitive ability (Fletcher-Watson et al., 2017; Totsika et al., 2010), with limited research in these areas and far more co-occurring identities to consider. Additionally, individuals who participated in this study were autistic adults connected to and engaged in online support communities (e.g., Reddit). As such, this study's population may not represent the general population of autistic adults, as individuals who found this study may have fewer support needs. Furthermore, data from the ADHD and control groups was obtained from the Hupfeld et al. (2019) study. As a result, researchers were unable to match groups based on participant characteristics and it is unclear if any of the Hupfeld et al. (2019) subjects had a co-occurring diagnosis

of autism. Future studies should aim to collect data across matched and more representative participant groups.

In addition, membership in study groups was based on the self-identification of participants in both this dissertation and the Hupfeld et al. (2019) study due to the method of data collection (online survey, retrospective). This method limited researchers' ability to screen individuals for diagnoses based on specific criteria. Furthermore, some argue that self-identification of these conditions is inaccurate (Lewis, 2016). However, there have been few efforts to involve autistic individuals in research overall (e.g., participation and interpretation of findings; Gillespie-Lynch et al., 2017; Howlin, 2013; Howlin & Magiati, 2017; Punshon et al., 2009) and it could be cumbersome for researchers to formally screen and diagnose participants prior to inclusion in research (in addition to other obstacles to autistic inclusion in research (Woods & Waltz, 2018). Further, individuals who respond to online surveys may be more likely to have support for their autism, awareness of their diagnosis, and/or be capable of functioning in a more neurotypical way compared to other autistic individuals (e.g., ability to verbally communicate). As such, it is important to consider the benefits and drawbacks of using self-identified participants in autism research such as accessibility and representation, respectively.

This study was also limited by the measures selected to assess the presence and perception of hyperfocus. First, the Hupfeld et al. (2019) questionnaire is newly developed and was designed for measuring hyperfocus within an ADHD population, which could affect the validity of its use with an autistic sample. Further, the scale created by researchers to assess perceptions of hyperfocus (EHFS) was newly created for

this study and yet to be compared to similar measures (or otherwise validated using other measures, such as expert validation), which is a consideration for future studies.

Additionally, scores on both measures were obtained by participant self-report which may increase the ecological validity of this study's findings, but impact construct validity when considering the impact of participant subjectivity. Similarly, data was only collected from the perspective of the autistic individual with no collateral input on how hyperfocus may impact others (e.g., family, friends, employers, etc.). Although this study was focused on prioritizing the delivery of the autistic perspective, the input of collateral sources would further contribute to the understanding hyperfocus in this population.

A final limitation of this study is lack of community input. Unfortunately, researchers were unable to have materials reviewed by an autistic consultant due to scheduling conflicts. This method was inconsistent with guidelines posited by the autistic community and may have resulted in limitations to the study's accessibility. For instance, several participants commented on this study's social media posts regarding the wording of questionnaire items and survey formatting. This lack of community perspective should be addressed in future research.

Future Directions

As this is the first study to investigate and support the presence of hyperfocus in autism, future research should aim to replicate findings and add to knowledge of this experience. Furthering the understanding of hyperfocus from both subjective and objective perspectives will allow for a more accurate understanding of autism and the support needs of autistic individuals. For instance, the impact of hyperfocus on areas of daily living (e.g., social, educational, occupational) should be explored to further

understand its impact on everyday life. Future research could include collateral (e.g., loved ones, employer, clinician) impressions of hyperfocus to explore the benefits and drawbacks to this construct in various environments. Further, there may be a benefit to re-examining the construct of hyperfocus in combination with various demographic factors (e.g., gender expression, level of disability) and co-occurring diagnoses, due to the differences observed in hyperfocus between autistic individuals with and without ADHD in this study. Other common co-occurring conditions, such as depression and anxiety, could impact an individual's ability to hyperfocus, thus providing additional diagnostic and treatment considerations. In general, much more research needs to be conducted before a full understanding of hyperfocus in autism is established.

In addition to the benefits of further exploring hyperfocus, the findings of this study suggest that the current conceptualization of autism is missing key aspects of the autistic experience. As such, a further exploration of the presence of strengths in autism and the benefit of incorporating neurodiverse perspectives into psychological research is vital. Further investigation is fundamental to an accurate understanding of autism, as most current conclusions were formed by those who “lack the lived experience” (Gillespie-Lynch et al., 2017, p. 1). As such, researchers should investigate the presence of strengths in other suggested areas of cognition (e.g., perception, reasoning, comprehension) and aspects of functioning (e.g., social, occupational) by autistic individuals. This exploration would support the development of more accurate diagnostic tools, which will allow future researchers to include subjective (e.g., self-report) and objective (e.g., neuropsychological tests) methods into future research. History has demonstrated that the understanding of autism has continued to change over time and future research should

aim to continue this development in efforts to better understand and support this community.

Conclusions

The field of psychology's understanding of autism has evolved significantly since its initial conceptualization. Despite this growth, current approaches to autism research and intervention are rooted in a deficit-based framework, which excludes the input of autistic individuals and the consideration of the lived experience. However, the neurodiversity movement and autistic advocates argue that features of autism are differences rather than deficits. Hyperfocus is one such feature of autism that has been identified by this community as not only a difference but also a strength. As such, this study aimed to further the conceptualization of autism by investigating the presence of and perspective on hyperfocus from the view of autistic adults involved in online support communities. Results demonstrated the highest instances of hyperfocus in autistic participants (with and without co-occurring conditions) and the perception of hyperfocus as beneficial, which is consistent with literature across multiple perspectives (e.g., biopsychological, cognitive, autism-led theory). As such, these findings have tremendous clinical implications regarding diagnostic and treatment practices with this community, while demonstrating the need for advocacy on the part of providers. Future research should continue this exploration of hyperfocus and the neurodivergent lived experience, as it is imperative to the field's continued understanding of autism. Additional investigation would also reduce the stigma surrounding autism, which is a significant issue across clinical and nonclinical settings. Further research, along with advocacy efforts by clinicians, will result in improved diagnostic and treatment practices and

identification of individuals. The potential for development in this area is vast and would affect the lives of countless neurodivergent individuals by validating their differences and providing meaningful supports.

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APPENDIX A

PERMISSION TO USE MEASURE

From: Hupfeld, Kathleen E <khupfeld@ufl.edu>
Sent: Thursday, May 21, 2020 11:40 AM
To: Higgins, Ashley <ahiggins@Immaculata.edu>
Subject: Re: request to use the Hyperfocus Questionnaire

External Email

This email originated from outside the Immaculata network. Please use caution when opening from unknown sources. If unsure, contact OTS at ext. 1234 or forward this message to Abuse@immaculata.edu.

[Immaculata University](#)

Hi Ashley,

Sorry for the delayed response! Thanks so much for your interest in our work! It sounds like your student has some super interesting work planned. I am curious to know how their results turn out... we originally were interested in digging further into ADHD comorbidities & possible relationships with HF; however, in our original sample since we didn't recruit specifically for things like ASD, we didn't have a big enough sample to do so. We definitely agree with the cost vs. benefit idea in ADHD, so interested to hear what you uncover in the context of ASD.

I'm attaching the supplemental info from the paper. This contains the full HF questionnaire. A few notes-- the questionnaire is LONG. We had an ongoing in person study with college students with ADHD with one goal being to shorten the questionnaire; however, this has been paused due to COVID-19. Our thought is e.g., using just the dispositional questionnaire, just scenarios, or just the school/hobbies/screen time would be sufficient, but we have not looked deeply into this yet.... considering e.g., an item response theory type analysis to identify the most important questions...

There is also the Ozel-Kizil Turkish questionnaire which we have had re-translated into English from Turkish. This one is shorter, but as we describe in the paper, we didn't think it captured HF as fully as our questionnaire. (We also didn't think the translation to English was optimal, so that's why we had a Turkish colleague re-translate it; the authors originally administered it in Turkish.) I am also attaching this, in case you find it helpful. In our study that was paused, we were also having subs answer the Turkish questionnaire so we could later do some comparisons & consider different methods for creating an optimal shorter HF questionnaire.

Please let me know if you or your student has any other questions & best of luck with your work!

Best wishes,
Kathleen

From: Higgins, Ashley <ahiggins@Immaculata.edu>
Sent: Tuesday, May 19, 2020 5:07 PM
To: Hupfeld, Kathleen E <khupfeld@ufl.edu>
Subject: request to use the Hyperfocus Questionnaire

APPENDIX B
ADULT HYPERFOCUS QUESTIONNAIRE

Adult Hyperfocus (HF) Questionnaire

Name or Subject ID:
Date:

Instructions: You will be asked to answer some questions about your feelings and experiences when you are doing activities that you enjoy. Please read all instructions carefully and answer each statement as accurately as possible. The entire test consists of five subscales (with 12-18 questions each), followed by a brief short-answer section.

Part 1/6: Dispositional HF

These 12 statements discuss some common feelings and experiences that might occur when people are doing activities that they enjoy or find rewarding. Read each of these 12 statements and then rate how often you had each feeling or experience **in the last year**.

1. Generally, when I am busy doing something I enjoy or something that I am very focused on, I tend to completely lose track of the time.	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
2. In general, when I am very focused on something or I am doing something that I find especially rewarding, I do not notice the world around me, and I won't realize if someone calls my name or if my phone buzzes.	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
3. Generally, when I am very focused on something or doing something that I find especially rewarding, I might accidentally miss meals, stay up all night, or keep doing the activity until I absolutely must get up to go to the bathroom.	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

<p>4. In general, when I am busy doing something I enjoy or something that I am very focused on, I find it very difficult to quit and move on to doing something else, even if I have a lot of other important things I should be doing instead.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>5. Generally, when I am very focused on something or doing something that I find especially rewarding, I can feel totally captivated by or “hooked” on the activity.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>6. In general, when I am busy doing something I enjoy or something that I am very focused on, I sometimes focus for far too long on a small detail of the task and avoid other important parts.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>7. In general, when I am very focused on something or I am doing something that I find especially rewarding, I can be unsure of what time of day it is or how much time has passed since I started the activity.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>8. Generally, when I am busy doing something I enjoy or something that I am very focused on, I don't react to any distractions (e.g., if someone talks to me).</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>9. In general, when I am busy doing something I enjoy or something that I am very focused on, I forget to attend to my personal needs (e.g., I forget to sleep or eat or I wait until the last minute to go to the bathroom).</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>

<p>10. Generally, when I am very focused on something or doing something that I find especially rewarding, I feel like I can't stop doing the activity, even if I have other more important responsibilities.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>11. In general, when I am busy doing something I enjoy or something that I am very focused on, I can feel completely engrossed or fixated with the activity.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>12. Generally, when I am very focused on something or doing something that I find especially rewarding, I can get "stuck" on little details that keep me from finishing other important parts of the task.</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>

Part 2/6: School HF

For experimenter use only:

Dispositional HF Subscale Score: ____ / 72*

*Scoring: 1-6 points per item ("Never" = 1 ... "Daily" = 6)

The next three sections discuss some common feelings and experiences that might occur when people are engaging in schoolwork, their hobbies, or screen time.

What is your favorite course that you have taken so far in college? This could be a class that you are currently taking. If you are not currently a college or university student, think back to your favorite college or high school course and answer these questions based on your experiences at that time.

Please write the name of your favorite course here:

When completing homework or studying for the course you entered above, how often do or did you experience any of the following:

1. Completely losing track of time while doing work for the class	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
2. Not noticing the world around you (e.g., not realizing if someone calls your name or if your phone buzzes) if you're working on homework or studying	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
3. Accidentally missing meals, staying up all night, or continuing to study or do work for the class until you absolutely must get up to go to the bathroom	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
4. Difficulty quitting or moving on from your schoolwork and starting a new task, even if this new task is more important or urgent	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
5. Feeling totally captivated by or "hooked" on completing your schoolwork or studying	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
6. Finding yourself too focused on a small detail of a task while avoiding	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

<p>other important parts of the task (e.g., spending too much time formatting your document instead of concentrating on writing the content of your paper)</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>7. Not realizing how much time has passed since you started your homework or studying</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>8. Not attending to distractions (e.g., not hearing someone talking to you) when you're doing homework or studying</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>9. Forgetting or failing to attend to your personal needs (e.g., not sleeping, missing meals, waiting to going to the bathroom) while you're doing homework or studying</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>10. Feeling like you can't stop doing your schoolwork, even if you have other more important responsibilities (e.g., an assignment that is due sooner for another class)</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>11. Feeling completely engrossed or fixated with your schoolwork or studying</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>12. Getting "stuck" on little details that keep you from finishing other important parts of the task (e.g., spending too much time trying to come up with one better word to use when writing a paper instead of focusing on the paper as a whole)</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>

Part 3/6: Hobby HF

For experimenter use only:

School HF Subscale Score: _____ / 72*

*Scoring: 1-6 points per item (“Never” = 1 ... “Daily” = 6)

What is your favorite hobby (e.g., practicing an instrument, playing a sport, making art, reading for fun)?

Please write the name of your favorite hobby here:

When engaging in activities related to the hobby you entered above, how often *in the last year* have you experienced any of the following:

1. Completely losing track of time while doing something related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
2. Not noticing the world around you (e.g., not realizing if someone calls your name or if your phone buzzes) while doing something related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
3. Accidentally missing meals, staying up all night, or continuing to do something related to your hobby until you absolutely must get up to go to the bathroom	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
4. Difficulty quitting or moving on from the hobby activity and starting a new	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

task, even if this new task is more important or urgent (e.g., to finish work for school or your job)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Feeling totally captivated by or “hooked” on doing things related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
6. Finding yourself too focused on a small detail of a task while avoiding other important parts of the task (e.g., spending too much time redrawing one portion of your art piece instead of concentrating on the piece as a whole)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
7. Not realizing how much time has passed since you started doing something related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
8. Not attending to distractions (e.g., not hearing someone talking to you) when you’re working on something related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
9. Forgetting or failing to attend to your personal needs (e.g., not sleeping, missing meals, waiting to going to the bathroom) when you’re doing something related to your hobby	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
10. Feeling like you can’t stop doing your hobby, even if you have other more important responsibilities (e.g., getting ready to go to class or your job)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

11. Feeling completely engrossed or fixated with the hobby activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
12. Getting “stuck” on little details that keep you from finishing other important parts of the task (e.g., spending too much time practicing playing one part of a song, instead of practicing the entire song)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

For experimenter use only:

Hobby HF Subscale Score: _____ / **72***

*Scoring: 1-6 points per item (“Never” = 1 ... “Daily” = 6)

Part 4/6: Screen Time HF

*What type of “screen time” do you most frequently engage in during your **free time** (i.e., **NOT** when you’re doing something related to your job or to your school)?*

Please choose one of the following:

- Watching TV or movies (on a TV, computer, tablet, or mobile phone)
- Playing videogames (including games on a gaming console, online games, and tablet or mobile phone games)
- Using social media on a computer or on your mobile phone (e.g., Facebook, Twitter, Instagram, Snapchat, etc.)
- Shopping online
- Using online dating websites or mobile phone applications for dating
- Generally “surfing the web” (e.g., reading news articles, looking up information using search engines, etc.)

Other (please list):

*When engaging in the type of screen time you chose above, how often **in the last year** have you experienced any of the following:*

1. Completely losing track of time while doing the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
2. Not noticing the world around you (e.g., not realizing if someone calls your name or if your phone buzzes) while doing the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
3. Accidentally missing meals, staying up all night, or continuing to do something related to the screen time activity until you absolutely must get up to go to the bathroom	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
4. Difficulty quitting or moving on from the activity and starting a new task, even if this new task is more important or urgent (e.g., to finish work for school or your job)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
5. Feeling totally captivated by or “hooked” on the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
6. Finding yourself too focused on a small detail of a task while avoiding other important parts of the task (e.g., spending too much time comparing prices and reviews online)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

and putting off a decision about something to buy)						
7. Not realizing how much time has passed since you started doing the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
8. Not attending to distractions (e.g., not hearing someone talking to you) when you're doing the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
9. Forgetting or failing to attend to your personal needs (e.g., not sleeping, missing meals, waiting to going to the bathroom) when you're doing the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
10. Feeling like you can't stop the screen time activity, even if you have other more important responsibilities (e.g., getting ready to go to class or your job)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
11. Feeling completely engrossed or fixated with the screen time activity	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
12. Getting "stuck" on little details that keep you from finishing other important parts of the task (e.g., spending too much time looking up recipe ideas online trying to find the "perfect" dish)	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>

Part 5/6: Scenario HF

<p>in hours.”</p>						
<p>4. “When I get really ‘into’ researching for a paper, I can have trouble stopping, even though I know that I need to go to class or that I need to work on something for another class.”</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>5. “When I’m working on motorcycles, I forget the world. I have a rush from how driving fast makes me feel, so I associate that with working on motorcycles...my mind just goes crazy, on ‘overdrive,’ and I can’t think of anything else. I’ll be in class and thinking about the details of how to wire my motorcycle. When I get into a project I really enjoy, I ‘go all out’ until I burn out.”</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>6. “When I’m shopping online for something—even just a new pair of running shoes—I can spend hours on my computer searching for the ‘perfect’ choice. I’ll search through website after website looking for the best deal, perfect color, coolest brand, and so on, and then I’ll read through as many reviews as I possibly can until I’m fully satisfied that I’ve found the best option.”</p>	<p>Never <input type="checkbox"/></p>	<p>1-2 times every 6 months <input type="checkbox"/></p>	<p>1-2 times per month <input type="checkbox"/></p>	<p>Once a week <input type="checkbox"/></p>	<p>2-3 times a week <input type="checkbox"/></p>	<p>Daily <input type="checkbox"/></p>
<p>7. “Sometimes, when I’m at the library and have my headphones in, it’s like</p>	<p>Never</p>	<p>1-2 times every 6 months</p>	<p>1-2 times per month</p>	<p>Once a week</p>	<p>2-3 times a week</p>	<p>Daily</p>

<p>no one else exists in the world. I won't even notice if everyone around me has left—but this only normally happens when I'm working on a project for a class that I really like."</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>8. "When I'm playing music or editing it, I can work endlessly without knowing that my entire day has passed me by. I'll come upstairs from the basement thinking it's still the early afternoon and the sun will have set already."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>9. "I get hooked on Netflix very easily and find that I cannot stop easily to get my homework done."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>10. "When I'm working in the lab, I can get so 'into' the work that I feel like there is nothing else I possibly could or should be doing. I feel like I'm all by myself, and I don't actually 'hear' what anyone else says, even if I act like I'm listening to them."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>11. "When I'm working on a craft project...I can repaint the same line over and over until it's perfectly straight and clean...even if I step back and it looks fine, I can spend so much time focusing on the little details like that."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>

<p>12. "I can play videogames for hours at a time without moving. I get so focused on the screen. When I'm playing videogames, my roommates say that the only way they can get my attention is to jump in my face or if they turn the TV off."</p>	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
<p>13. "After I start a project like writing a new computer program, I stay up so late just thinking nonstop about the code for it. I can't clear my head and put it away for the next day. I stay up all night itching to get back to working on the program. Half the time, I just end up getting up and going back to my computer at 3 AM and then I can't focus in class the next day."</p>	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
<p>14. "For me, it's writing. I get so into my personal creative writing that I can't stop, even when I know I have homework due or I should be getting ready for work or class. I've been late to class many times because I've just <i>had</i> to finish that last paragraph or sentence."</p>	Never <input type="checkbox"/>	1-2 times every 6 months <input type="checkbox"/>	1-2 times per month <input type="checkbox"/>	Once a week <input type="checkbox"/>	2-3 times a week <input type="checkbox"/>	Daily <input type="checkbox"/>
<p>15. "When I'm on the Internet, it's almost like I'm under a hypnotic</p>	Never	1-2 times every 6 months	1-2 times per month	Once a week	2-3 times a week	Daily

<p>spell. I'll check my email, respond to Facebook messages, go through friends' pictures, read some news articles, update my other social media pages...it just goes on and on, and sometimes I can't control it. I tune out the world and immerse myself in the Internet, even when I know that I'm not doing anything that meaningful online."</p>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<p>16. "I'm a perfectionist in my work, so I can get stuck on little details easily. I'll spend almost an hour making sure that my bibliography formatting is correct, even when that is only worth a small percentage of my actual grade."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>17. "When I'm really focused on something, it just feels like this is the right thing to be doing. Sometimes I miss meals or accidentally stay up all night because I get so invested in what I'm doing."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>
<p>18. "If I get on the Internet—especially looking at things like BuzzFeed, Facebook, or Pinterest—I'll always think that it's only been a few minutes, but then I'll see the time and realize I've been online for an hour or two."</p>	<p>Never</p> <input type="checkbox"/>	<p>1-2 times every 6 months</p> <input type="checkbox"/>	<p>1-2 times per month</p> <input type="checkbox"/>	<p>Once a week</p> <input type="checkbox"/>	<p>2-3 times a week</p> <input type="checkbox"/>	<p>Daily</p> <input type="checkbox"/>

For experimenter use only:Total Scenario HF Subscale Score: _____ / **108***School Scenario HF Subscore: _____ / **36** (Q1 + Q4 + Q7 + Q10 + Q13 + Q16)Hobby Scenario HF Subscore: _____ / **36** (Q2 + Q5 + Q8 + Q11 + Q14 + Q17)Screen Time Scenario HF SubScore: _____ / **36** (Q3 + Q6 + Q9 + Q12 + Q15 + Q18)

*Scoring: 1-6 points per item ("Never" = 1 ... "Daily" = 6)

Please use the space provided to answer the following questions. Please provide as much detail as you can.

1.) What types of activities tend to cause you to become very focused (e.g., schoolwork, a certain hobby, surfing the Internet)? List as many activities as you

can think of.

2.) Please describe in as much detail as possible a time when you were very focused on something.

- How long did this episode of focus last?
- How did you feel during it?

- Did you accomplish something in the end (e.g., an assignment for school, a piece of artwork, another type of project, etc.)?

For experimenter use only:

Participant Score Summary:

Dispositional HF Subscale Score: _____ / **72**

School HF Subscale Score: _____ / **72**

Hobby HF Subscale Score: _____ / **72**

Screen Time HF Subscale Score: _____ / **72**

Total HF Score: _____ / **288** (sum of four scores listed above)

Scenario HF Subscale Score: _____ / **108***

****The Scenario HF Subscale should be scored and considered separately from the other five HF scores***

APPENDIX C
RERB APPROVAL

**IMMACULATA UNIVERSITY RESEARCH ETHICS REVIEW BOARD
REQUEST FOR PROTOCOL REVIEW--REVIEWER'S COMMENTS FORM
(R1297)**

Name of Researcher: Rachel Nicholson

Project Title: Subjective Experiences of Hyperfocus In Autism: A Neurodiversity Perspective

Reviewer's Comments

Your proposal is **Approved**. You may begin your research or collect your data.

PLEASE NOTE THAT THIS APPROVAL IS VALID FOR ONE YEAR (**365 days**) FROM DATE OF SIGNING.

Reviewer's Recommendations:

Exempt
 Expedited
 Full Review

Approved
 Conditionally Approve
 Do Not Approve

Marcia Paris

July 1, 2021

Marcia Paris, Ed.D.
Chair, Research Ethics Review Board

DATE

APPENDIX D
CONSENT FORM



1145 King Road, P.O. Box 500, Immaculata Pennsylvania 19345 -0500

COLLEGE OF GRADUATE STUDIES

CONSENT FORM

We are currently engaged in a study of the subjective experience of hyperfocus in autistic adults. To help us gain further insights into this area we are asking you to complete the following survey. This survey will take approximately 15 minutes to complete.

You may benefit from increased insight into your experiences as a result of participating in this research project. It is also possible that you may feel inconvenienced when completing the study survey. Researchers attempted to reduce this risk by presenting survey questions in a clear and concise manner. To protect your privacy, the data you will provide will be recorded anonymously and your participation will be held in the strictest confidence via the use of a random study identification number. Your participation in this study is on voluntary basis, and you may refuse to participate or stop this survey at any time without consequence or prejudice.

We welcome questions about the experiment at any time. Any questions you have about the research can be directed to Dr. Ashley Higgins, Department of Psychology & Counseling, ahiggins@immaculata.edu. Any questions about your rights as a research subject may be directed to Dr. Marcia Parris, at ext. 3210, mparris@immaculata.edu. Her office is Room 130 Loyola Hall.

Selecting "yes" below indicates that you have read and understand the contents of this consent form and that you agree to take part in this study. Participating in this study will not waive any of your legal rights. Please select "no" if you are no longer interested in participating.