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# The Right Kind of Attention

*A qualitative analysis of the ADHD community on Instagram*

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# Abstract

Attention Deficit Hyperactive Disorder (ADHD) has been a contentious disorder for years and incorrect beliefs and assumptions about the disorder are still common both in the medical community and the public's perception. Previous research has exemplified this by demonstrating that the representation of ADHD in traditional mass media consists of few depictions and homogenous stereotypes. In recent news, the growing ADHD community on social media has been widely documented and discussed. This study was conducted to further deepen the insight and understanding of this phenomenon through qualitative interviews with five ADHD creators on the platform Instagram. By incorporating users' agency this study demonstrates the ways lingering outdated assumptions on the disorder has impacted several large demographic groups. The findings of this study argues that the rising popularity of the growing ADHD community on social media can be understood as a reaction to the neglect these individuals have experienced over the years.

*Keywords: social media, ADHD, stigma, mental disorders, media representations, Instagram, qualitative interviews, content creators.*

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# 1. Introduction and Previous Research

The understanding and definition of *Attention Deficit Hyperactive Disorder*, commonly referred to as ADHD, has evolved significantly over the years. However, incorrect stereotypes and beliefs about the disorder are still common in both the medical community as well as the public's perceptions (ADDitude Magazine, 2022; Horton-Salway, 2012). Research suggests that the reason that ADHD has become such a contentious disorder may stem from the fact that the scientific and medical diagnostic specifications were developed alongside socio-cultural representations of the disorder concurrently influencing the diagnosing and identification process of ADHD (Horton-Salway, 2012:1085; cf. Singh, 2002a; 2002b; Conrad and Potter, 2000; Mayes and Rafalovich, 2007)

Today the DMS 5 (Diagnostic and Statistical Manual of Mental Disorders) categorizes the disorder in three different 'kinds': predominantly hyperactive-impulsive presentation, combined presentation, and predominantly inattentive presentation (Williams, 2022). The latter of the presentations used to be called ADD; this definition has been medically inaccurate since the 90s, but the continuous use of this term can be exemplified as one of the lingering incorrect assumptions. The two most persistently believed myths about ADHD are that it is a disorder that mainly affects males, and only occurs during childhood (ADDitude Magazine, 2022). These dated beliefs have shaped much of what is associated with the disorder and likewise can be found in the most common stereotypes, in characters in popular culture as well as coverage in news media (Englandkennedy, 2008; Hinnant and Ray, 2009; Clarke, 2011; Horton-Salway, 2012).

Over the last two years, several articles (Clark, 2021; Diaz, 2022; Ruskin, 2022) highlighting how women, AFAB<sup>1</sup>, and people of color are discovering in adulthood that they have ADHD through popular social media platforms like TikTok and Instagram. The content on these platforms displays how symptoms and behaviors present in other demographic groups can be connected and explained as undiagnosed ADHD. In a recent study (Yeung, Ng and Abi-Jaoude, 2022), TikTok's top 100 most popular videos about ADHD were classified in three categories as either *useful*, *personal experience*, or *misleading*. The results showed that 52% of these videos were labelled as misleading. Consequently, the researchers call for more awareness regarding the spread of medical misinformation and the potential consequences of the growing

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<sup>1</sup> Acronym meaning "assigned female at birth".

popularity of this social media phenomenon. The juxtaposition of the concern that medical misinformation on social media may contribute to mis- or overdiagnosis and the positive narratives of individuals finally getting the right diagnosis, invites further inquiry on this topic.

Research articles from the early 2000s focus on the depiction and representation of the disorder in different types of mass media. The result of these studies highlights that the representation of ADHD in newspapers and magazines present a large amount of terminology describing danger, display risk-society discourses, as well as a heavily scattered view of the medicalization of the disorder (Hinnant & Ray, 2009; Clarke, 2011). In movies and on television the representation of characters with ADHD are few, and the depictions are often stereotypical, negative, and harmful (Englandkennedy, 2008). Additionally, deeply embedded in the media discourse on ADHD is a gender-bias towards boys (Horton-Salway, 2012).

More recent research has shifted, alongside society's focus, from traditional mass media to modern social media platforms. These studies and articles present similar results and discussions on danger, fear, and medicalization (Pavlova and Berkers, 2022; Yeung, Ng and Abi-Jaoude, 2022; Clark, 2021; Diaz, 2022; Ruskin, 2022). One of the most significant transformations from traditional mediums to modern-day social media are users' control, agency, and impact on their media consumption along with new opportunities to create their own content. This aspect has been overlooked by previous research, however, and needs to be explored further. Therefore, this paper aims to provide more insight into this disputable disorder through qualitative interviews with individuals currently making content about ADHD on social media. This study intends to answer the following three questions:

- In what ways have the lingering incorrect stereotypes and homogenous depictions of ADHD affected these individuals, both online and offline?
- What are the biggest challenges and benefits of advocating for ADHD on social media today?
- How is connection and community around ADHD created and maintained on Instagram?

## 2. Methodological Framework

This study started as an in-depth exploration of the large body of earlier research on the representation of ADHD in different types of mediums throughout the years. The decision to carry out an extensive review was based on Flyvbjerg's (2011:130) argument for the importance

of having a socio-historical foundation when conducting *phronetic research*. Having a comprehensive understanding of the findings and questions of past scholars intended to help ground this study in its proper context before formulating the direction of the research.

The critical studies of ADHD representation in mass media (cf. Singh, 2004; Englandkennedy, 2008; Hinnant and Ray, 2009; Clarke, 2011; Horton-Salway, 2012), as well as recent papers on health- and misinformation (cf. Furzer, Dhuey and Laporte, 2022; Gascon *et al.*, 2022; Pavlova and Berkers, 2022; Yeung, Ng and Abi-Jaoude, 2022), and news articles about the rapidly growing ADHD community on social media (cf. Clark, 2021; Diaz, 2022; Ruskin, 2022) have all failed to accurately take users' agency into account. For this reason, the aim of this study is to incorporate the perspective and lived experience of content creators to deepen the insight of this phenomenon.

To understand the development and significance of the increasing ADHD content and community on present day social media, focus was placed on a small, specific group of creators. Flyvbjerg (2011:136) argues that exploring the meaning of smaller daily practices can provide general significance to a much larger phenomenon. In likewise manner, Sullivan (2020:317) concludes that the development of technology and the transformation of audiences' stem from "a complex interplay of agency and structure", and that the best starting point for future research is in the smaller, lived experiences of everyday life. By understanding and exploring how structural factors influence these creators, as well as how these actions in turn have structural consequences, this study aims to incorporate an analysis on both actor level and structural level (Flyvbjerg, 2011:138; Sullivan, 2020:317). Given these points, to explore the active role of content creators – the way they use social media to find community, challenge dated stereotypes, educate, and inspire – semi-structured qualitative research interviews were chosen as the main method for collecting empirical material for this study.

## 2.1. Conducting Qualitative Research Interviews

The most important factor in the implementation of this study was finding the right people to participate in the interviews. In order to be able to put the empirical material derived from these interviews in historical context of earlier research, and in light of recent news on the growing community on social media, the interviewees needed to fit into a specific demographic. Namely, individuals identifying as female, or AFAB, diagnosed with ADHD in adulthood, and are actively creating content about the disorder online.

The content creators were found on the platform *Instagram*. The decision to not expand the search to other platforms was mainly based on the intended focus on one specific group and the similarities and differences within that group. With more time and resources, interviewing several demographic groups across different platforms, and additionally comparing the results between them would most likely result in an interesting analysis. However, this was not realistic within the timeframe and workload of one student. In the final analysis, the interview group consisted of five women who had all been diagnosed with ADHD in adulthood and are active creators on Instagram, where they make content about the diagnosis.

They were first contacted through the platform's own direct message function – unless email was specified on their profile as the preferred form of communication. In total, 22 creators were contacted. Out of the nine that responded, two declined and two never followed through, adding up to a total of five participants. The interviews were conducted via the video platform Zoom. This allowed for flexibility since all five participants were located in different parts of the world – Denmark, Ireland, Bali, Sweden, and Japan. All interviews were conducted in English and lasted between thirty and ninety minutes.

After the creators had agreed to participate, they were sent a follow-up message outlining the purpose of the study and its design; and before the interview, an email<sup>2</sup> was sent out with the Zoom-link and further instructions explaining the ethical and moral aspects of participation (Kvale and Brinkmann, 2015:93). Notably, one non-standard feature of this study concerns confidentiality. Normally, it is expected that no data will be disclosed that could help identify the study's participants, in order to protect their privacy (ibid.). None of the participants' social media names will be presented in this text, as this was deemed to not provide any additional information beneficial to the research. Since these women have a public persona on Instagram, however, their identities have not been anonymized. As this paper will be in the public domain, other precautions have been made to protect them and their privacy.

Additionally, regarding the ethics of confidentiality, any specific mention of ADHD creators not participating in the study have been removed or generalized (Kvale and Brinkmann, 2015:95). In likewise manner, in the message exchange prior to the interviews, it was stated that if answering a question felt uncomfortable or too private, the interview would just move on to the next one. During an interview, one of the participants disclosed something about her

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<sup>2</sup> See Appendix 1

personal life and stated that she did not want that to be public information. This was also noted again during the transcription of the interview to ensure that this stayed private.

### *2.1.1. Interview Guide & Themes*

As someone who recently got diagnosed with ADHD as an adult, I approached this study and the interviews with personal experience, understanding, and knowledge of several aspects of this topic. While the ADHD community on social media wasn't a part of my own diagnostic process, I found great comfort in the community afterwards. As noted by Kvale and Brinkmann (2015:131) before contributing new knowledge to a phenomenon, a theoretical and conceptual understanding is required "to be able to pose relevant questions" (ibid.). While my interest and knowledge contributed to the initial design, I assumed that the participants would contribute new and unexpected information that I had not considered or known of. Therefore, initially the interview guide had three main themes reflecting the three research questions – the first theme covered the participants experience with traditional media, the second theme explored their role as a content creator, and the final theme encompassed relations and interactions with others on social media<sup>3</sup>. However, because the study incorporated exploratory elements in its design, *ADHD-Coaching* became an additional part in the interview guide (ibid., 139).

The last section, *personal*, did not follow the order of the other sections in the interview guide. Instead, it was treated as a 'floating' set of questions, meant to be asked where it felt appropriate during the interview. This was based on what Kvale and Brinkmann (2015:157) write about keeping a good dynamic dimension and how the questions "should promote a positive interaction, keep the flow of the conversation going, and stimulate the subjects to talk about their experiences and feelings" (ibid.). As the interview process went on, this model of moving sections and questions around was applied more frequently. The design and development of the interview guide started shortly after the extensive review of previous research, setting the theoretical dimension of the interview early on. Once the interviews began, the balance between the theoretical dimension and dynamic dimension happened quite naturally (ibid., 156).

### *2.1.2. Transcription & Transparency*

After each interview, the audio files were first transcribed using the automatic transcription software *HappyScribe* and then reviewed several times by me throughout the duration of the study. Instead of listening to the audio once, transcribing the conversation, and only working

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<sup>3</sup> See Appendix 2



with the written text, the possibility of analyzing the audio recording and the written text concurrently had several benefits. Most importantly, by listening to the audio recording several times, any discrepancies regarding mishearings or misinterpretations could be clarified (Kvale and Brinkmann, 2015:211).

The repetition of listening to the quotations used in this study resulted in them turning into ‘sound bites’ for me, then by having someone else read the quotes I could correct the written words until they matched those spoken. Therefore, included in the quotations are *italics* to clarify a stressed word. Interruptions or important emotional aspects are presented in brackets. I have stayed as true to the transcripts as possible, but necessary cuts of the quotations have been inevitable, mostly due to the transformation from a verbal conversation into a written text. As Kvale and Brinkmann (2015) point out “an eloquent speech may appear incoherent and repetitive in direct transcription, and an articulately argued article may sound boring when read aloud” (2015:204).

### 3. Theoretical Framework

To understand the foundation which this study builds upon there are three main theoretical elements that need to be clarified further. First, we need to have an awareness of earlier research’s perspective on the impact mass media have on the public perception of mental disabilities. Then, we need insight into how the development of technology alongside rapid digitalization have changed previous understandings of audiences and community. Lastly, there will be a clarification of this study’s perspective on stigma and ADHD. By defining these theoretical concepts, accompanied terminology, and demonstrating how they are connected, the analysis in the upcoming chapter will become clearer.

#### 3.1. Media’s Portrayal of Mental Disabilities

The first fundamental element in this study is based on the idea that media have a significant impact on the public’s perception of mental disabilities and mental health. Sieff (2003:260) concludes that “[c]onsistently over time, media coverage of mental illnesses has been overwhelmingly negative and often inaccurate” and suggests that these bad representations contribute to existing negative perceptions. In likewise fashion, Englandkennedy (2008) points to media’s impact on “the formation of specific mental constructs of people with disabilities,” (ibid., 92) but also proposes that improved media production and the display of better representation might “provide a means for changes in such perceptions” (ibid., 91).

14 years ago, Englandkennedy (2008) published a thorough overview of the research regarding the representation of characters with ADHD in movies and television over the years. The article observes and examines the changing stereotypes and continuous modes of mental disorders. The study claims that there are few representations of ADHD and that they are harmful and negative. In her conclusion, she writes that the most likely way this could improve would be through activist groups or individual activists acting as “media watchdogs” and interfering by raising awareness, questioning bad representation, and educating individuals in media production (ibid., 113f).

### 3.2. The Transformation of Audiences

The second theoretical element of importance in this study, and one of the most significant developments in the 21st-century media experience, is the media audiences’ shift from “passive information receivers into engaged information producers” (Sullivan, 2020:266f). An understanding of what has allowed media audiences to transform into media creators is necessary before attempting to explore the growing communities on social media and their potential future.

By referring to research by Jenkins and Napoli, Sullivan (2020:268f) concludes that through technological developments like rapid digitalization<sup>4</sup> and convergence<sup>5</sup>, there have been major changes impacting media institutions and audiences. The expansion of media channels and media platforms have divided audiences into smaller and smaller groups, something that has made traditional forms of audience measurements significantly more difficult (ibid., 269). Additionally, because of the control media audiences now have over their consumption, this newfound independence from traditional forms of media distribution has made it harder to locate and advertise to them (ibid.). This independence has shifted the technological structure of the internet – more specifically known as *Web 2.0*. The opportunities for individuals to spread, share, and reproduce entertainment, news, opinions, and thoughts, have led to what Henry Jenkins (2006:290, cited in Sullivan, 2020:281) called *participatory culture*. These changes have made audiences more engaged in their consumption, thus making them more ‘dangerous’ to traditional media (ibid., 280) Sullivan points out that “online media have become battlegrounds for the control and interpretation of popular culture" (ibid., 296).

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<sup>4</sup> Digitalization - the process of how media images and sounds are recorded and transmitted (Sullivan, 2020:268).

<sup>5</sup> Convergence - the process that “allows media content to be displayed on any number of devices” (Sullivan, 2020:269).

Connecting Sullivan’s summarization of how the development of the internet has allowed passive audiences to become empowered and independent media producers, with Englandkennedy’s reasoning regarding how media producers can impact the public perception on mental disorders, presents an interesting foundation of theoretical perspectives that will be explored further in the analysis of this study.

### 3.3. Perspectives on ‘Stigma’ and ADHD

To get a deeper understanding for the growing ADHD community on social media, a necessary inclusion of literature from the social psychological field have been applied to the empirical material in this study. In the preface of his book *Stigma*, Erving Goffman defines the term as “the situation of the individual who is disqualified from full social acceptance” (1963:9). Goffman’s book was originally published 60 years ago and unsurprisingly contains certain perspectives that are very dated today. Nevertheless, his descriptions of the emotional and social implications in interactions between stigmatized and non-stigmatized individuals have been helpful as an overall reference guideline to explain important aspects in the analysis.

Goffman categorizes three types of stigmas: First, physical stigma such as abnormalities or deformations of the body. Next, stigma of character traits, which he describes as “blemishes of individual character perceived as weak will, domineering or unnatural passions, treacherous and rigid beliefs, and dishonesty” (ibid., 14). Lastly, the stigma of group identity that comes from belonging to a certain race, religion, or nation. Nevertheless, the same sociological feature affects all three – the stigmatized individual possesses an undesired differentness that is unexpected from the anticipation of the non-stigmatized individuals (ibid., 15). He calls what’s expected an individual’s *virtual social identity* and what is actually possessed their *actual social identity*. A discrepancy between the two will result in a *spoiled social identity* that “has the effect of cutting him off from society and from himself so that he stands a discredited person facing an unaccepting world” (ibid., 31).

Combining modern definitions and explanations from web-based medical articles with Goffman’s sociological ideas have aimed to bring a broader understanding to the empirical material in this study. For example, Goffman’s book covers different ways a stigmatized individual can try to apply different responses in their everyday lives to seem more ‘normal’. Today we describe someone with ADHD who is trying to act like they don’t have ADHD as *masking* (Saline, 2022). More specifically, terminology connected with ADHD, as well as

specific terminology coined by Goffman to explain stigma, will be explained in further detail in the analysis.

While there is still a large group of individuals who do not acknowledge the existence of ADHD as a proper diagnosis, this essay will not entertain or elaborate on this belief beyond this paragraph. The arguments and facts presented in this article are based on the latest scientific research and definitions of the disorder. Continuously throughout the text any generalized statement about the disorder – mentions of symptoms, clarification of terminology tied to the disorder – will have a reference to an article published by *ADDitude Magazine*. Since 1998 they have been the leading media resource and network for anyone interested in the disorder, and all articles referenced have been reviewed by their medical advisory panel (*ADDitude Magazine*, n.d.).

## 4. Analysis – Interviews

This study aims to explore three main themes through a series of interviews with the content creators who have been diagnosed with ADHD as adults. First, discussions of representation and stereotypes were conducted with the intent to compare the women’s personal experiences with the results and conclusions of earlier research. Second, questions about the participants’ own accounts and their role as content creators aimed to highlight how this group deals with stigma, misinformation, and the relationship between creative and educational content. The final theme initially intended to encompass the positive and negative aspects of community and interaction, but additionally resulted in an observation and discussion of the development of modern digitalization.

### Overview of the participants in the interviews:

NAME	LOCATION	DIAGNOSED AT AGE	FOLLOWERS
Ailín	Ireland	32	28.7k
Felicia	Sweden	25	2521
Kate	Japan	34	35.2k
Mette	Denmark	25	66.2k
Nicole	Bali	33	113k

### 4.1. Representation & Stereotypes

Leading off the interviews, the content creators were asked about their view of the importance of neurodivergent characters in entertainment through traditional mediums, such as movies and television shows. Ailín, Felicia and Mette all expressed the importance of representation, but stressed the need for *different* and *more* types of representation in entertainment today:

**Ailín:** It's kind of one depiction across the board of stereotypes. So, I think now that we know more about the neurodivergent spectrum and how different people can present, then I think it's super important to have the different representations, for sure.

**Mette:** [...] I think that's the issue with a lot of it – that it kind of gets thrown around and not represented in a way that's correct, and that can be really harmful. So, it's not just important that there's representation, it's also important that the representation is accurate and respectful, so it doesn't create more stereotypes than there already are.

The depiction of individuals with disability and mental illness in mass media have changed a lot over the years; Englandkennedy (2008) concludes that there has been a general shift from

characters with disabilities being primarily portrayed as villains, victims, and monsters, to being replaced with characters that are meant to be seen as super-human, and eventually just human; this is not, however, the case for ADHD. Instead, she highlights the lack of representation of the diagnosis and proposes that the existing deceptions “reflect and reinforce social concerns and negative stereotypes” (2008:112).

In the conversations with the women, several different examples of dated stereotypes and the public’s incorrect beliefs about the diagnosis were given. In the following three subsections the recollections they shared will be compared with observations established in previous research as well as compared to the most recent medical facts. The first subsection, *Hyperactive Boys and Forgotten Girls*, covers the connection between gender, stereotypes, and ADHD. The next section, *Superpower*, focuses on the participants’ experiences with the superhero trope. The final section, *The Right Diagnosis*, explores the polarizing discussion of the growing rates of ADHD and the women’s take on the debate.

#### *4.1.1. Hyperactive Boys and Forgotten Girls*

Following the introductory question, the respondents were asked if they could think of any good or bad examples of ADHD they had seen depicted in a movie or on a television show. When discussing a bad example, Ailín mentioned the American television show *Desperate Housewives* from 2004, where the character Lynette starts taking her sons medication:

**Ailín:** [...] the twins were diagnosed with ADD, as they used to call it. They were just, you know, the naughty kids. Everyone in the neighborhood thought they were so naughty and bold, and the mum was so stressed, she started taking their Adderall... [laughs] dips into the Adderall.

This example demonstrates results found in previous research observing how mothers have been portrayed as responsible for their disruptive sons and how gendering is deeply embedded in media discourse of ADHD (Singh, 2004; Englandkennedy, 2008; Horton-Salway, 2012). Throughout the interviews different aspects of gender came up several times. For example, Ailín also described what she considers to be the most stereotypical portrayal of ADHD in movies and on television:

**Ailín:** [...] it’s the hyperactive, disruptive, naughty boy kind of a thing.

Kate brought up an episode from the American animated television show *The Simpsons*. The episode, called *Brother’s Little Helper*, was also mentioned in Englandkennedy’s article from

2008. In the episode, the character Bart experiences paranoia as a side effect of self-medicating after taking too many pills. In the article, Horton-Salway argues that Bart's parents are not concerned about their son's diagnosis until he steals a tank and knocks a satellite from the sky and starts creating problems that affect others. She claims that the episode portrays the parents as overly trusting of doctors and that the episode "clearly portrays Bart as maladjusted and potentially criminal" (2008:110) Kate, on the other hand, had another interesting take on the episode:

**Kate:** But if you look at [Bart] as a character and he's always getting in trouble, he gets bad grades, he hates school, he can't read, he's not like his bright sister. On the other hand, if you look at both Simpson children as having ADHD, that would make sense too, right? That would be a better balance.

This possibility of both the Simpsons siblings having ADHD encompasses a more diverse representation of the disorder – while, arguably, still falling into the stereotypical hyperactive young boy and the overachieving perfectionist that are much more common in young girls with ADHD<sup>6</sup> – this way of presenting the two characters would put the episode in a new light. Even though Kate didn't consider the episode to be good representation, she acknowledged that it was one of the better examples of the television she watched growing up:

**Kate:** It was the 90s... very inappropriate.

The timing of when a character's disability is revealed affects how the audience responds - if the disclosure happens early, the viewer might make inaccurate assumptions or project negative cultural stereotypes. On the other hand, stereotypes might be questioned if the audience has already formed a close identification with the character before their disability is revealed (Englandkennedy, 2008:96). This explanation can be applied to a character like Bart, as well as the other examples given by Kate:

**Kate:** [...] if you have a character, like Michael in *The Office* or something, who is clearly ADHD, or Andy in *Parks and Recreation* [...] these are just characters who are ADHD in their – like just the way the characters are written, it doesn't say it directly. [...] I feel the more interpretive side of characters in that way, is better than directly saying these characters are neurodivergent.

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<sup>6</sup> "A subtle symptom presentation with a greater likelihood of inattentiveness marks the ADHD experience for many women and girls, who are not outwardly disruptive to others /.../ Research shows that women are highly motivated to hide their ADHD symptoms and compensate for them" (ADDitude Magazine, 2022).

More of the responses from the interviews likewise indicate that the women prefer when the audience can make their own interpretation. This seems to stem from seeing too many bad depictions or narratives made by neurotypical writers and actors displaying outdated and damaging stereotypes. Another example of this, brought up by Nicole, was the controversy regarding the Australian popstar Sia's debut film *Music* released in 2021. In the movie, the neurotypical actress and dancer Maddie Ziegler, who previously starred in several of Sia's music videos, was cast as a nonverbal autistic teenage girl. The movie also contained scenes depicting the use of restraints on autistic people (Miller Hyndman, 2021):

**Nicole:** When the whole Sia drama was happening [...] she had the girl that dresses up as her [...] playing an autistic woman who wasn't actually autistic. There was big negative feedback of not being represented correctly.

How media is consumed by audiences affects how meaning is created; when engaging mindfully, an individual will consider and reflect on what is being presented with regard to the knowledge they previously had – here new attributions and models of understanding can be constructed, and old stereotypes questioned (Englandkennedy, 2008:94f). Benkler (2006, cited in Sullivan 2020:281) argues that the technical developments that have allowed audiences to edit video, audio and pictures have contentiously resulted in a deeper, more critical, and overall, more engaged understanding of the media we are consuming. In addition to these two points, the opportunity to express opinions and find like-minded individuals through social media platforms has resulted in the distance between media producers and audiences shrinking immensely – impacting and affecting the traditional media industry.

While few of the women could come up with any good representation of neurodivergent characters in entertainment, aside from audiences' own interpretation of traits and characteristics, a notable moment in one of the interviews was Nicole mentioning an episode of the Netflix comedy-drama *Heartbreak High* from 2022:

**Nicole:** [...] for the first time I saw sensory overload<sup>7</sup> being depicted accurately on TV it almost made me cry, like I felt so understood. [...] she represents us so accurately, or for some of us, so accurately since she presents so differently.

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<sup>7</sup> “Sensory processing disorder (SPD) is a neurological condition that interferes with the body's ability to receive messages from the senses, and convert those messages into appropriate motor and behavioral responses /.../ It inhibits a person's ability to filter out unimportant sensory information, like the background noise in a bustling café, making them feel overwhelmed and over-stimulated in certain environments /.../ SPD can be a stand-alone disorder, or it may co-exist with other disorders, such as ADHD” (Rodden, 2023).



The show stars the Australian actress and autistic self-advocate Chloe Hayden who worked closely with the writing team on the show that “has been widely praised for its accurate portrayal of a young autistic person” (Topsfield, 2022).

#### 4.1.2. *Superpower*

In her study of the media representation of ADHD, Englandkennedy (2008:97) utilizes the categories of negative stereotypes and results presented in earlier studies (e.g., Kriegel, Nelson, and Bogdan *et al.*) on how the portrayal of characters with disabilities have changed in film and television over the years. She concludes that there are no positive portrayals of persons with disabilities in early films between the 1920s–50s. In the 60s, heroic portrayals were presented to audiences of physically stigmatized characters who overcome their limitations through accomplishments considered beyond the expectations of most humans (*ibid.*, 98). Then, in the 70s, this portrayal was taken further presenting characters with some sort of exceptional gift accompanying their disorder. A common example would be a blind character with excellent hearing, like the movie *Daredevil*. Most of these portrayals, however, were said to be offensive to individuals with disabilities – demeaning the less dramatic struggles of everyday life (*ibid.*, 99).

Even though the general media representation of people with disabilities have continued improving over the years, Englandkennedy’s (2008:101) study shows that this is not the case for depictions of ADHD. Supporting this finding is the fact that, in recent years, several examples fitting the trope of superhumans and heroic portrayals of ADHD can be found in mass media. The most compelling evidence of this is the fantasy novels about *Percy Jackson* by Rick Riordan. The story centers around the twelve-year-old protagonist who discovers that he is a son of Poseidon and a demigod; like all demigods he has ADHD and god-like battle instincts, as well as dyslexia, which purportedly makes it easier for him to read Ancient Greek than English (‘Percy Jackson & the Olympians’, 2023). The book-series has become highly successful and sold over 180 million copies worldwide (Disney, 2022). In another study, which examines gender and ADHD in UK newspapers over a 2-year period, Horton-Salway concludes that three stories published about women “were adult celebrities narrating career and success stories despite ADHD” (Horton-Salway, 2012:1092).

During the interviews, the participants were asked about how they felt about ADHD being described as a superpower. None of the participants were confused by the question or unfamiliar with the connection, highlighting the fact that the superhero trope both exists and has become

quite common in relation to ADHD. For Nicole and Ailín, the question was initially met with a lot of emotions:

**Nicole:** [Audible exhale] That's one. So... [laughs] Okay. I'm – because of the life that I've had, and because now I know all the things that were tied to my ADHD symptoms, that has been a really challenging thing for me. There was a point where I almost-, I considered stopping doing what I was doing because there were so many people talking about, "ADHD is a superpower! Don't call it symptoms, say traits!"

**Ailín:** Okay, so, I have a particular problem with that, and I think there's loads of reasons why. Personally, I don't really relate to that, and I have a slight problem with [it]. Because for me, I have found that my ADHD has been very disabling. For some reason, I always come across superpower being put up in the complete opposite meaning to disability.

These reactions align with what earlier research says about the response to depictions of the superhero trope – rather than uplifting individuals with disabilities, these narratives reinforce the idea that something extraordinary is required for acceptance (Englandkennedy, 2008:98f):

**Ailín:** I always get kind of a little bit annoyed when people say to me like, "oh, you know, Richard Branson has ADHD" and all of these, like, really rich, famous people. I'm like, that does not impress me in the slightest. Like, it doesn't impress me!

There is a collective agreement between the women throughout the interviews that making a connection between having ADHD and having superpowers should only be done by individuals with an actual diagnosis:

**Felicia:** For me, I hope that it's only people with ADHD that are saying it, and maybe not people without ADHD.

Kate acknowledges the dichotomies that are often presented in these discussions, and several times notes her choice of normalizing staying in the middle of the discussion to fight these contrasting positions:

**Kate:** I feel that dichotomy is aimed to divide the neurodivergent community too, because I feel you can't be neutral in it. I don't like when people say it's not a superpower. I don't like when people say it is a superpower. I would say I am very neutral on this [...] I think it's harder for people with ADHD to accept that it's a disability versus a superpower. At the end of the day, if it makes you feel better that your ADHD is a superpower, that's great. But if you don't want to adopt that language, that's fine too.

Felicia had a similar reasoning when discussing the superhero trope, emphasizing the importance of letting the individual themselves decide how they want the narrative to be told, through an entertaining comparison between *the Hulk* and *Superman*:

**Felicia:** In the beginning, Bruce Banner probably doesn't think that "wow, I've got superpowers!" He's probably like, "This is ruining my life. This is the worst thing ever". But then when he learns more about himself and he can take control of it [...] he can help save the world. [...] You can't see it like something that is super good like, "wow, Superman's power. He's like a superhuman and he's better than everyone else" because no, then ADHD is not that way.

None of the women express identifying strongly with the superhero trope. Overall, the interviews show that the women would rather highlight the overcoming of everyday struggles and traits as superpowers than coupling it to famous people doing something extraordinary:

**Ailín:** I'm more impressed with people who have struggled so much and they're able to kind of improve their own lives and be honest about the struggles that their ADHD has brought them.

#### 4.1.3. *The Right Diagnosis*

A study, examining the different ways ADHD was socially constructed in Anglophone North American magazines between 1988-2008, found consistent evidence of the growing rates of ADHD diagnosis in both children and adults. Several stories, however, expressed elements of skepticism, ambivalence, and doubt as to what degree the disorder should be considered real, and/or a problem (Clarke, 2011). Rates of ADHD diagnosis have continued increasing up to present time and remains one of the more prevalent debates in relation to the disorder today (Cf. Furzer, Dhuey & Laporte, 2022; Gascon *et al.*, 2022). While this recent research confirms that misdiagnoses only occur in small demographic groups, the public's belief that over diagnosing is common, as well as a problem, is something the content creators have noticed both in real life as well as on social media:

**Kate:** When I say that ADHD is under diagnosed - a lot of people do not like to believe this. Which is weird, because if you do any, *any* search about if ADHD is over diagnosed or under diagnosed, it's completely under diagnosed. It is only over diagnosed in very small groups of people – usually, white and black little boys in America, right? Everywhere else, it's far under diagnosed. But that one gets me in trouble.

**Felicia:** They do it with the perspective of "is this really correct? [Are] there this many people, or are people getting over diagnosed?" Always like assuming that people are getting over diagnosed.

In her interview, Felicia reflected further on the effect this belief has had on her personal life:

**Felicia:** I think it's sad because I always feel like then when you don't look like the stereotypical version of ADHD, then of course, it will be *me* they look at it like, "well, she must be one of those that got her diagnosis-, like over diagnosed, that she shouldn't really have one".

She continued describing how difficult it was for her to find diverse information in Swedish about the different presentations of ADHD, more specifically, what it can look like in adult women. She had more luck after one of her friends told her to turn to sources and research from America instead. While this was around five years ago, a recent portrayal of ADHD in Swedish news demonstrates that stereotypical depictions of the disorder are still common.

In the months leading up to the 2022 Swedish Election, the Moderate Party in Stockholm proposed that all five-year-old children in 'vulnerable areas' should be given rapid tests for ADHD. The purpose of the motion was stated to make treatment available early as a way to reduce gang crime. The party's justice spokesman Johan Forsell told the Swedish newspaper *Expressen* that there is a preponderance of individuals with an ADHD diagnosis in the country's jails, and therefore, interfering early would be an effective way to prevent new recruitments to the gangs. The proposal, however, was met with a considerable amount of criticism from other political parties, doctors, as well as the public (Fagerström, 2022; Österman, 2022). Felicia, who also lives in Sweden, described during the interview that the representation of ADHD in this example is the one she often has seen portrayed in the news:

**Felicia:** That people with ADHD are sort of-, they are troublemakers. [...] Let's not focus on any of the socio-economic issues. Let's blame it all on the biology again.

The motion highlights several elements from earlier research regarding the representation of ADHD in the news: an overbearing terminology relating to an implication of danger, a heavily medicalized focus, media's ongoing risk-society discourses and gender bias, and the ever-changing yet continuous stigmatization of the disorder (Hinnant and Ray, 2009; Clarke, 2011; Horton-Salway, 2012). Nevertheless, the negative response and criticism of the motion displays a growing understanding of ADHD. Likewise, it shows a general awareness of how

stigmatization of mental disorders in media coverage can portray unfair and damaging stereotypes that negatively impact the public's perception (Sieff E, 2003:230).

Yochai Benkler (2006, cited in Sullivan, 2020:266f) observed how the development and expansion of the internet are transforming audiences from simply being consumers to information producers. This has continued to expand even further with the development of social media platforms. The recent debates in mass media over whether social media may contribute to self-diagnosing, and the increasing number of individuals seeking medical care because of this, highlights that the fear of over-diagnosing is still prevalent today (Yeung, Ng and Abi-Jaoude, 2022).

Instagram has given these women the opportunity to create their own portrayals of living with ADHD, where they can choose what aspects to highlight, what misassumptions to challenge, and what to celebrate:

**Nicole:** I think generally most people understand the concept of what they're getting into when they go on to social media, I would hope... That it is just anybody putting stuff out there. I think you kind of have to know to take it for what it is. This is information from your peers.

**Kate:** [...] if you're just self diagnosing, that doesn't harm anybody anyway? And if you're diagnosed by a professional, then you can't be like, "well, the information they got off TikTok was wrong" because the professional just diagnosed them with ADHD.

Nicole's real-life story of not recognizing the disorder in herself for years because she did not fit into the stereotype she knew, additionally highlights the importance of mass media finally addressing these issues:

**Nicole:** I had worked with neurodivergent [people] for like twelve years and then I didn't even recognize it myself, you know, because it presents *so* differently in assigned female [at] birth, women, or adults.

## 4.2. Creating Content about ADHD on Instagram

The second theme touched on in the interviews is the diverse aspects of being a content creator on social media. The first subsection, *Lost in the Feed, Fighting the Algorithm*, will explore how the women deal with things that are outside of their control, such as invisible algorithms, negative comments, misinformation, and how they distinguish themselves among other

accounts. The following section, *Put the Fun in Dysfunctional*, will highlight the reasons behind the women's active choice of incorporating lighthearted aspects into their content.

Instagram allows several different ways for users to post their content. What began as a platform for sharing pictures now allows shorter videos (*reels*) - something that has increased in popularity through the rapidly growing video-only platform TikTok. One distinctive categorization we can make of ADHD-related content is the difference between solely informative posts – created to explain, inform, correct, and educate – and more humorous posts that display experiences and behaviours related to individuals with ADHD. Unsurprisingly, there's a lot of content that incorporates both aspects, for example, a humorous situation to catch the recipient's eye followed by a more informative explanation of said situation. When asked about what kind of content perform better on their accounts, the creators mentioned posts with characteristics relating to relatability and understanding:

**Ailín:** On my page, definitely the longer posts. [...] I think that's to do with shareability, simplicity of understanding the thing, and relatability. I think that number one is relatability and how people can relate to it, see themselves in it, and understand it through their own perspective.

**Kate:** I would say actually sometimes the sillier ones might do better...? Same like for my reel, I found that audio of "you can't just lay down and die" and I'm just rolling on the floor, and that also got really a lot of response to people. I guess it was very relatable.

On Ailín's page it's the longer more informative posts, while for Kate it's the humorous reel that receives the most engagement recently; still, they both encompass modes of recognition with or for their audience. Research has argued that one of the main reasons behind our attachment to social media is the exchange of meaningful experiences – something these companies are very aware of, and try to encourage, with the intention of us continuing to use their site (Miguel, 2018:68f). While the respondents all want to reach and connect with as many people as possible, they reveal a disinterest in chasing views or participating in trends just for the sake of the trend:

**Nicole:** When I go through different topics, I can tell which ones are getting more engagement. But that's not how I base what I create, at all. [...] I don't base content on views.

Throughout the interviews, it's clear that the women are aware of the skepticism toward the growing social media phenomenon of ADHD in the press (Clark, 2021; Diaz, 2022; Ruskin,

2022) and express that they want to distance, or distinguish themselves, from some ADHD accounts. Kate expressed a growing frustration over creators who make ADHD videos that display vague and generalised behaviours and traits. While these creators, indubitably, have shared thoughtful and scientifically based facts about ADHD, after seeing several vague posts from one creator Kate could not handle it anymore and lastly blocked their account:

**Kate:** [That video] has absolutely nothing to do with ADHD. *Nothing* at all to do with ADHD, right? There's not even anecdotal evidence. There's not *anything* that says that that's a real thing, right? That is just *your* personality quirk. That is just like a generalized statement, right?

She continues by comparing it to one of her own posts. The reel, which is her most successful with 1.4 million views, is about organizing your home, placing things in different piles and what happens when you find something that does not fit into any of the existing piles. It might seem like this could be just another generalized thing that a lot of people relate to without necessarily having to be neurodivergent, however, this is not the case entirely. Kate, who outside of social media works as an ADHD educator and learning consultant, explains the scientific reasoning behind the behavior displayed in the reel:

**Kate:** [...] we can talk about associative thinking – how we categorize, how our brains need to visually represent things, and how we're going to create this organizational cell which is based on some sort of science-like trait of people with ADHD. Particularly, visual tracking, and associative thinking, right?

One of the biggest concerns in recent research about the growing popularity of health-related content on social media is users' difficulty knowing which of these relatable humorous reels are actually based on scientific facts and which ones are mainly meant for entertainment (Yeung, Ng and Abi-Jaoude, 2022:900). This dilemma is not just placed upon the user, or the platform for that matter, but a concern and frustration the creators in this study also take upon themselves:

**Ailín:** [...] if I do like a shorter post, or like something that isn't as detail oriented as my usual posts, I get more criticism [...] Then I'll see another account, like an account who has like 100,000 followers, or they have really huge audience, and they will [talk] consistently about the low dopamine, which we know now isn't completely accurate [...] nobody will pull them up on it. So, I find that really interesting.

Creating content on the platform includes navigating through obstacles which are outside of the women's control. The following subsection will dive further into what this means and how they deal with the less positive parts of being a content creator.

#### *4.2.1. Lost in the Feed, Fighting the Algorithm*

The 'explore' feed on Instagram, like the 'for you' page on TikTok, allow users to find things that the platform thinks might be suitable for them by the use of *proprietary algorithms* (Ruskin, 2022; Yeung, Ng and Abi-Jaoude, 2022). These algorithms are used for many reasons, such as separating spam in our inboxes, suggesting songs on Spotify, or in this case, sorting through an excessive number of posts on social media. Even though algorithms are a fundamental tool that have been around since the beginning of computer science, there has been a lot of debate and research regarding the impact that these machine-learning algorithms have on users in the present day (Garfinkel, 2017). An awareness that the algorithms have an impact on the creators' outlook was mentioned several times:

**Ailín:** [...] maybe I'm just in the echo chamber.

**Kate:** Because if you look at my feed, my particular feed, it's ADHD, ADHD, ADHD. I actually had to create a new account and not like any ADHD stuff because the algorithm was just, "you only like ADHD". I actually want to know about other stuff [laughs].

Mette also reflected on this when she did not have an answer for a question about her view on the discussions regarding ADHD medication on social media:

**Mette:** [...] I don't know, that could also be my own bias about the fact that it just doesn't really interest me. So maybe I'm just scrolling past it, I don't know? But I haven't seen it in a lot of posts actually.

When Mette doesn't engage in content about ADHD medication, the algorithms sort it out from her feed; nevertheless, that does not mean it's not there. This was perfectly exemplified by the other creators having several comments on their experience with the topic on social media:

**Nicole:** In the beginning, I was really careful about not saying whether or not I was on meds because I didn't want to influence somebody either way, because it's a personal choice between them and their doctor.

**Kate:** If I'm talking about something very serious – such as medication, if I use a statistic – I definitely make sure I have a reference for it. I usually cite references.



**Ailín:** Yeah, there's a lot of discourse and arguments that I do see about fighting about meds or fighting about the medicalization. [...] One of my pet peeves just in general is like, spirituality and the whole natural methods and "meds are demons" and this kind of thing. I mean, to be fair, I am very pro science, I'm very pro medicine.

Another interesting reflection was made by Kate. In the summer, she was promoting one of her classes and made a comment about the effects of misogynistic systems, something that resulted in a lot of comments and engagement:

**Kate:** My friend who is a content coach, she helps people with marketing, does say, like a little bit of those controversial buzzwords, so like "misogyny", can really make your posts grow.

All of these different examples and observations from the creators supports the idea that since the algorithms are hidden, they have few ways to control what gets shown to their audience, and in what way (Garfinkel, 2017; Miguel, 2018:68) – something that has resulted, for many of them, in a perpetual feeling that every post needs to be well-made, with proper references to scientific research and use of popular and appropriate hashtags, resulting in a very time-consuming never-ending task:

**Ailín:** [...] it takes me ages to *actually* do work on a post, and I have so many that are unfinished with the research. Sometimes it's hard to find the accurate research, and it just gives me PTSD from doing my dissertation and constantly researching scientifically.

Consequently, even after they have put a lot of effort and time into creating a post that they are proud of, they might still get far less engagement than another post on a much lighter or generalised subject because of a certain word or something they did not plan for. Naturally, a more popular post will garner more positive reactions, but also more negative comments. I spoke to Mette a couple days before Christmas. She told me that on account of the added workload from her day job before the holidays, combined with the increasing numbers of negative comments on her account, she had decided to not only take a break from the account but started contemplating whether it would be worth continuing to create content:

**Mette:** Actually, now I've had to take a break for the past couple of weeks from creating content because of this. [...] I just had to say I'm not engaging with any of this because people have been actually really, really vicious and they've been really nasty in the way that they speak about it. [...] It definitely impacts how I work, and it's definitely making me consider which type of content I make, and if it's worth the backlash sometimes?

While the ongoing discussion on misinformation, health information, and the consequences of self-diagnosing on social media are important, the lived experiences of the creators suggest that the rising amount of general awareness about this phenomenon has resulted in more negativity, scepticism, and criticism in the comment sections. The harsh environment has led many of these creators to take a step back from posting, or not engaging with their audience in the same way they used to:

**Nicole:** [Before] I tried to answer every comment, you know, follow my DMs, post at certain times of the day. [...] I don't think being on social media all the time is good for your mental health. And again, I like to practice what I preach, so I stay very far away from that, to be honest. I try not to engage at all as far as like checking views, or I don't even reply to comments anymore because I try... I know that I can produce better content, and show up more, the less I engage in that side of things.

The interviews suggest that the most draining parts of keeping up their social media profiles are centered around negative comments and hidden algorithms. Nevertheless, the women also frequently mention their active choices around how they create content. The next subsection will highlight the positive aspects of living with ADHD, the supportive community, and how to make the good outweigh the bad.

#### *4.2.2. Put the Fun in Dysfunctional*

Throughout the interviews, specific terminology and the same metaphors were repeated by several of the respondents when answering different questions and sharing their experience, for example:

**Nicole:** If I hear another person talk about like, squirrels [laughs] and stuff like that, I'm done. The squirrel thing is super annoying. The distractibility part... yes, and I'm so tired of hearing people say that. [...] I think when people make these, it's all in good fun I guess, but when people make these jokes about: "oh, a squirrel like ADHD" I think it really takes away from the iceberg of symptoms that are going on.

**Kate:** [...] if it's not written indirectly but whenever they try to make somebody like ADHD, it's always like, "oh, squirrel, take your ritalin". Then that-, it's just all the other negative stereotypes.

The comparison between squirrels and people with ADHD, as well as other repeating terminology, can be understood through what Goffman (1963:15) calls *stigma terms*. In everyday life, non-stigmatized individuals apply certain attitudes and actions in social

interactions with someone with a stigma. These are constructed from a *stigma theory* – “an ideology to explain his inferiority and account for the danger he represents” (ibid.) because the definition of an individual with stigma is that they’re not quite human for the non-stigmatized. The example from the interviews, comparing a person with ADHD to a squirrel, might seem harmless. However, hearing a constant repetition of minimizing metaphors and unfair comparisons, understood from Goffman’s description, would suggest that for the stigmatized individual these words are a constant reminder of being different, and less human (ibid.).

When discussing the process of creating content, the interviewees were questioned whether they pay extra attention to the use of certain terminology, or whether this is something they actively think about:

**Nicole:** Well, I would never use *guided language*, right? So, I'm not going to tell somebody how they're feeling, or make things absolute. So, I'm going to say, "RSD<sup>8</sup> *may* cause you to feel so in such and such way", right? It's always going to be *may* or *can*, but never absolute language. I think that just comes from a background of being like trauma informed. You never want to tell people: “This is how it is!” Because everybody is different.

Felicia recalls telling her old therapist that she understands the theories and methods given to her but she’s struggling to apply them in real life, and instead of being met with compassion she was just met with silence:

**Felicia:** Then my therapist just looking at me like, "huh, what does this-, I don't know what this means” sort of made me feel like the most hopeless case ever. Like, wow, she's speechless. She does not know what to say. Does this always work for other patients? Why doesn't she have anything to say?

Similarly to Nicole, Felicia now feels strongly about not minimizing anyone’s problems or questions when answering questions on her account:

**Felicia:** I don't want to like, make someone feel more bad about themselves or their ADHD, but I also don't want to trivialize their problems.

Few of the women describe having an easy or good experience with life either before or after getting their diagnosis. Even though the interviews are filled with a lot of sad stories and heavy subjects, the content these women post to Instagram reflect models of positivity,

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<sup>8</sup> RSD is an abbreviation of Rejection Sensitive Dysphoria: “When you have ADHD, your nervous system overreacts to things from the outside world. Any sense of rejection can set off your stress response and cause an emotional reaction that's much more extreme than usual” (Watson, 2022).

encouragement, understanding, and humor. It could be suggested that they embody the treatment they would have wanted to receive themselves. The response from the women indicates that incorporating variations of lighthearted aspects have been an active choice that they have all made:

**Mette:** [...] from the beginning when I started doing it, that was the main theme, that was the main focus. It's kind of shifted a bit towards educational content, but I think it is important to be uplifting, but more of all to be compassionate, to kind of try to look on the bright side, but also to be realistic and compassionate towards the struggles that people have.

### 4.3. Community & ADHD-Coaching

The final theme in the interviews aims to analyze the growing ADHD community on social media that has been widely documented in the news. The first subsection, *Finding Your Place*, highlights what this entails for the five women, both online and in real life; how connection is built and maintained through Instagram; a discussion on privacy; and the impact of their online presence on their life offline. The second subsection, *ADHD-coaching*, was originally not a part of the study but throughout the interviews revealed itself to be just as important and interesting. Thus, this section will attempt to explain what ADHD coaching and mentorships are, what it means for these women, and how it has impacted their lives.

#### 4.3.1. *Finding Your Place*

In the categorizations of stigma, Goffman categorizes the distinction between whether an individual's *virtual social identity* and their *actual social identity* is something noticeable immediately as *the discredited*, or not known upon first interaction as *the discreditable* (1963:57). In the latter categorization, most individuals have learnt what is considered to be 'normal' and what should be stigmatized. Therefore, when an individual learns later in life that they are not 'normal' they presumably might experience discomfort in re-identifying themselves and might develop some sort of disapproval of themselves as stigmatized (ibid., 48). Mette, who at the time of writing has almost 66.2k followers, shared that she did not post any pictures of her face or interact with followers through stories or reels in the beginning:

**Mette:** [...] it had a lot to do with that I wasn't fully accepting of myself as having ADHD. If someone I knew would see it, and I hadn't told them about it, I would be worried about that. It was kind of being - sort of paranoid about who's going to discover this and what am I going to do if they all of a sudden know?

For all respondents in this study, their ADHD diagnosis has been something they've had to come to terms with later in life. However, four out of the five women revealed that they had known that something was not right for a long time, and had been trying to identify the cause for years before getting the right diagnosis:

**Ailín:** I struggled with my mental health for a very long time, you know, was in therapy since I was 19, in and out of you know psychiatrists' offices, and just really struggled with my mental health. I was always given diagnosis of anxiety, depression, PTSD, and then bipolar, borderline personality disorder, like, so many different things.

**Nicole:** I didn't get my diagnosis until I was about 33, and before that I got diagnosed with everything under the sun, like so many of us. Anxiety, depression, BPD, borderline, all of it. But nobody could explain to me what was actually going on. And I really struggled with addiction for most of my life as well because I was self-medicating, and it was my coping skill to get through everything.

After being diagnosed late in life, the combination of wanting to find others with similar experiences and wanting to share their own story led them to online platforms where they found and became a part of a growing community. Scholar Raymond Williams described communication as “the process of making unique experiences into common experiences” (1961/1965:55, cited in Bolin *et al.* 2016:56):

**Ailín:** I was very passionate about speaking out about ADHD and how it presented differently in different types of people and talk about my own experience.

**Nicole:** I was like, oh my gosh, I want to find my people, I want to talk to people about it.

**Mette:** I started it because I was diagnosed earlier that year with ADHD and I was learning a lot about it, and it was really important for me to share all that I learned. So, it was kind of part of the process for me to learn about myself and help other people understand that as well.

Goffman (1963:31f) writes that most individuals with what he calls a *spoiled identity* will at some point in their life come across *sympathetic others* that will accept them. The most common sympathetic other will be someone who shares the same stigma. The connections the respondents have found on Instagram largely fall in line with what Goffman describes: “the comfort of feeling at home, at ease, accepted as a person who really is like any other normal person” (*ibid.*). All participants describe how being a part of the ADHD community on Instagram have led them to make several close connections to other creators:

**Mette:** I have a few people that I do talk to frequently, and that's from having this account, I wouldn't have met them or wouldn't have talked to them otherwise if I hadn't been doing this. So that's pretty cool.

**Kate:** I've made really good friends. I really like my content creators. I don't meet them, but we know each other, we support each other.

After getting their diagnosis and before creating their own accounts, all of the women describe following other ADHD creators on the platform. When asked about connections with other creators, Nicole recall how seeing the positive community was one of the reasons she wanted to create her own account:

**Nicole:** Everyone is incredibly supportive, and we check in with each other. It's a really, really welcoming community. It's kind of what drew me to it in the first place.

The connections and support are not limited to the community of creators, but extends to their followers as well:

**Ailín:** As I said a while ago, I have regular people who follow my page and will send me lovely messages and they will always reply to my stories and just kind of like egging you on. I don't know many of these people and they're just so, so lovely.

The creators were asked whether they've changed their mind over time in regard to sharing personal experiences – especially as their follower counts grow. Ailín confessed that after creating her account, she kept her profile secret for a month because she was so terrified. She does not experience the same fear anymore since she has made important connections and feels supported by the community. The growing number of eyes watching her, however, have made her feel like she needs to be more private:

**Ailín:** Yes. It's so funny because as I started off, I was a lot more open - even though I was more scared. And as the audience grew, I have to become more and more private.

Mette, on the other hand, describes how her confidence has grown with her follower count, leading her to being more open and sharing more of herself as a person and her life:

**Mette:** I decided last year that I wanted to try and sort of introduce myself as the creator and get more personal. That was really tough in the beginning, but the more I've done it and the more the account's grown, the more people that engage with the stuff that I make. It has been a really positive feedback loop in that way that I've felt more emboldened to share more of myself.

In her book, *Personal Connections and Intimacy in the Age of Social Media*, Miguel (2018:128) discusses what the difference between *privacy* and *intimacy* looks like in current online relationships. She defines privacy as “the state of control over personal information (confidentiality) or physical access to the person” (ibid.) and writes that traditionally, privacy could be defined in opposition to publicity. When asked about sharing personal experiences with a large audience, Kate said that she tries to not let the numbers on the screen impact her, but is somewhat concerned by the thought of someone finding or following her in real life:

**Kate:** I would say, the only thing I get concerned about is if there's going to be crazy people more than anything else. If I'm shooting [content] around my neighborhood or something like that, my mind goes through the extreme dark place of somebody stalking me or something.

Privacy used to involve a restricted area, or a private sphere, where individuals would create and develop meaningful relationships away from others. The internet has, however, complicated the management and control of personal information, and as a result, also changed the definition of privacy. The aspects that define virtual relationships regarding privacy and intimacy are subjective for each individual. For someone else, sharing personal experiences about their diagnosis with an unknown number of people may feel uncomfortable and crossing a privacy line (Miguel, 2018:218). However, for these women, this has been required to educate and make meaningful connections. The way they define privacy can be, like Kate mentioned, the physical distance she has to her audience, or while Mette now feels comfortable talking to her followers in her pyjamas, she is clear about respecting her partner’s boundaries on privacy:

**Mette:** I don't share my partner on my account because he's not super comfortable with social media. [He] doesn't mind me doing it, but he's not super comfortable with it.

As shown above, most of the discussions regarding privacy and sharing personal experiences to a large audience extend to questions of what effect these women’s online presence have on their lives outside of social media.

#### 4.3.2. *ADHD-Coaching*

Goffman (1963:38) writes that no matter the size of a stigmatized group, there will be some sort of public presentation, and as this study has attempted to highlight, there are very few examples of representation of this demographic group. Keeping this in mind, Goffman argues that when a stigmatized individual finds themselves in some sort of higher position, whether this is political, financial, or occupational, “a new career is likely to be thrust upon him, that of representing his

category” (1963:39). The growing ADHD community and these para-social relationships have, for many of the creators, additionally led to the opportunity of self-employment in the definition of *ADHD-coach*:

**Ailín:** [...] I found out about ADHD coaching, and I went for coaching myself, and it was fantastic. So, I said, "hm, maybe I can look into this as a career?" Because I had done like different types of careers, and nothing really ever stuck. I love being an ADHD coach. So that's how it happened and it's the most ironic job in the world, but it's amazing [laughs].

Felicia, who is currently studying to become a therapist, shares that she eventually wants to do ADHD-coaching but feels like she needs more qualification first:

**Felicia:** That's the goal, but I haven't started. [...] I feel like I want to be careful because people with ADHD, we often have other – like we have anxiety, or maybe depression, or other stuff we are dealing with as well. I really like to learn about those stuff and where you need to be extra careful. Because I don't want to be that coach, or that person, who is like, "well, you can just do it like this" and it makes the person maybe feel worse about themselves, like I did, when I was in therapy, before I got my ADHD diagnosis.

Felicia's reasoning also echoes Mette's thinking on the topic, who previously worked with ADHD mentorship and coaching but decided to not continue:

**Mette:** I think my talents are elsewhere. [...] ADHD is complex, and I think it requires a bit of training on how to do that sort of session. So, I kind of quickly realized that I didn't want to go too far into that realm unless I had some more training and that's not been possible at this current point.

It is clear throughout the interviews that all of the creators take the role of ADHD-coaching very seriously. Nicole, Ailín, and Kate, who do coaching work presently, all have some sort of background in education, mental health, disabilities, or other credentials that help qualify them for their coaching positions. Multiple times during the interviews they mentioned an awareness of how they bring their personal knowledge of living with ADHD into their coaching, but also that if someone approaches them with something outside of their expertise, they are upfront and clear about this:

**Nicole:** RSD, burnout, addiction, those are ones that I have a lot of personal experience in addition to professional experience. [...] relationships, friendship, any sort of people things – I have not figured that out yet. So, like, well, I can give some advice but that's not an area I specialize in.



**Kate:** But if somebody asked me something about Bipolar, OCD, or anything I don't know - I don't know, sorry. But I think that is hard, because I think that's the people pleasing aspect of ADHD too, that it's hard - it's like that you want to have the followers, you want to help anyone - but you need to be responsible and being like, "I don't have enough expertise on this to help you. I can't speak about BPD, or bipolar, or OCD."

In light of Goffman's observations on stigmatized individuals, the importance of learning to live with a spoiled identity and sharing this knowledge with others seems to be one of the biggest parts of ADHD-coaching (1963:31):

**Nicole:** I facilitate the peer factor for the most part because I think one of the biggest pieces is healing this internalized guilt, and shame, we got growing up [with] undiagnosed ADHD, and all the negative feedback we got.

**Ailín:** [...] even though all my clients love the relatability factor of me having ADHD, I do struggle still, of course. I still am hesitant to kind of share sometimes how chaotic my house is, or how messy my desk is, when there's people coming to me.

Ailín's struggle with wanting to remain in her professional role as a coach, and at the same time receiving trust from her clients when she shares her personal difficulties, highlights some of the complexity of this mediated relationship. The lack of co-presence between people in online interactions makes building relationships hard – to establish intimacy one must share personal experiences, which requires a lot of trust, although one of the most effective ways to build trust is sharing personal experiences (Miguel, 2018:129).

On the other hand, the mediated aspect of these online relationships also offer the creators some freedom; specifically, in the different ways technology today allows them to organize and control spatial and temporal constitutions (Thompson, 2011):

**Nicole:** I started kind of connecting with people on Instagram and then ended up doing [coaching] myself. Especially because I live on an island in Bali, so it's a little bit harder to make those connections. [...] this has worked out to be my dream job in a way that I am in full control of my schedule. I work things around. [...] my groups are for me first thing in the morning, so I don't get any anxiety about it throughout the day.

The technical development and the expansion of the internet has also changed the traditional relationship between media producers and consumers. To illustrate how unknown artists today can bypass traditional media's institutional gatekeepers, Sullivan (2020:266), uses the example of Rebecca Black's song *Friday*, and the successful fantasy novels by Amanda Hocking. He

writes that if Rebecca Black had to go through record labels and music companies, her song may never have seen the light of day. Nevertheless, “a vast network of always-on, plugged-in Internet users catapulted her into online infamy” (ibid.) which resulted in television and radio having to play catch up to her fame. Similarly, after being rejected by publishing companies several times, Amanda Hocking decided in February 2010 to upload her novel to Amazon and sell it directly to consumers. By July that same year, she was selling 100000 books per day (ibid.).

As can be seen through the women participating in this study, it’s revealed how this underrepresented demographic group has been let down for decades, particularly by the educational system and the medical community. The consequences of this let down, however, has led them to find community and solidarity on social media – getting caught up in what has been growing to become another widely documented social media phenomenon:

**Nicole:** I think I did hit a niche that was growing at a certain time. Not that I tried, it just happened.

Because of this, and through this growing community, traditional mass media have started reporting more on the different representations of ADHD as well as other demographic groups, leading more individuals to follow and interact with these creators. The community they have built through social media has, as discussed above, enabled them to expand on this further, creating an opportunity for self-employment based on sharing their knowledge and experiences with their diagnosis to others, something that still feels uncomfortable for some of them:

**Nicole:** I'm always worried like, “I hope they're happy”. It's so weird for me to even take money from people. I've never been in charge of that side of the business before [...] I just want to do a really good job [...] I get the positive feedback and stuff – it’s all worth it, like much more than-, it outweighs the anxiety that I feel about things, I guess [laughs].

Sullivan (2020:281) observes how the development of modern technology has made it possible for media audiences to transition from the role of passive media consumers to that of media producers. In his book he quotes several scholars and researchers arguing that these new opportunities to re-create and modify old content, as well as sharing and engaging in new content “are the logical extension of the theories of active audience interpretation and creation found in cultural studies research in the 1990s” (ibid.). This study, arguably, proposes that the example of the ADHD-coaching business can be viewed as a further extension of this technological development. By providing knowledge, understanding, medical research, and

support in the gaps where traditional institutions have failed this demographic group, some of these women have become self-sufficient through a virtual community built on the intentions of helping others.

## 5. Conclusion

In recent years, the rapidly growing ADHD community on social media has been extensively documented in the press alongside studies concerning the possible consequences of this phenomenon (Yeung, Ng and Abi-Jaoude, 2022). In contrast to those studies, by accurately evaluating users' agency through a series of interviews, this study has presented results of lived experiences and perspectives of five creators making content about ADHD on Instagram.

This study's first key finding is that the few and homogenous depictions of ADHD described in research from more than ten years ago are still present in entertainment today (Englandkennedy, 2008; Horton-Salway, 2012). The participants in this study describe a preference of letting audiences do their own interpretation of behaviors and traits in characters rather than seeing bad depictions written by neurotypical screenwriters and producers. This response can be seen as a consequence of the lack of good representation of neurodivergent characters over the years. The way social media has provided a space for individuals to connect and discuss these interpretations (Sullivan, 2020) arguably also contributes to this reasoning. Another consequence of the lack of diverse representation of ADHD in mass media can be understood through the women's stories of not recognizing the disorder in themselves because they did not fit into any stereotype. Along with the emotional responses apparent in the interviews while discussing these topics, the value of personal choice and reflections for individuals who have recently found a place and community is further emphasized.

As noted by Sullivan (2020:266), one of the most significant developments in the 21st-century media experience is the audience's transformation from "passive information receivers to engaged information producers" (ibid.). Analogously exemplified in this study, social media has provided an extraordinary opportunity for these women to make their own representation of ADHD, challenge outdated stereotypes, and question bad depictions. The second key finding of this study is that one of the biggest challenges of advocating for ADHD on social media are handling aspects that are out of the creators' control. While they value the importance of science-based content, the invisible algorithms (Garfinkel, 2017; Miguel, 2018), for example,

make it hard for them to control what posts get shown to their followers and on the explore feed to other social media users.

These two findings bring us to the last question of this study, namely, how connection and community is created and maintained on Instagram. As noted by Goffman (1963), for stigmatized individuals, the feeling of acceptance can often be found with someone who shares the same stigma. In this case, the creators have been able to make several close connections with other creators and followers with ADHD because of social media. During the interviews, they describe how their real-life experiences with bad treatments and unhelpful advice have influenced how they now approach their account and interact with their followers. Through understanding, compassion, and the sharing of experiences some might find too private, they have been able to build and maintain several online relationships (Miguel, 2018; Goffman, 1963). Additionally, understanding the ADHD-Coaching business as a further extension of the transformation in audiences from media consumers to producers, and as a continuing development of modern technology and community, is arguably the most significant finding in this study.

As mentioned in the methodological framework, future research could expand on this analysis further by interviewing more demographic groups, by interviewing both other content creators on other platforms, and incorporating the opinions and experience of followers. While this study chose to not include those who do not believe ADHD should be considered a proper diagnosis, incorporating that group may add interesting nuances in a future analysis.

To conclude, the recent critical articles that have highlighted concerns of misinformation on health-related content on social media contributing to mis- and overdiagnosis of ADHD have failed to take users' agency into proper consideration. This study argues that the lack of good and diverse depictions of ADHD in media representation reflect a real-life neglect on a large demographic group of individuals that have been going on for decades. The newfound interest in this community advocating for ADHD online may continue to contribute to positive impacts, changing of outdated lingering stereotypes, and a broader understanding – if it's allowed the right kind of attention.

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## 7. Appendices

### 1. Pre-Interview Email with Zoom-link

Hi [REDACTED]

Hope you are well!

I am attaching the link to the Zoom meeting in this email. Please prepare ahead of time by downloading or updating the Zoom app to ensure full functionality in the meeting. You should not need any special credentials to access this meeting, however, if you get a chance to test that everything works prior to the interview, I would highly appreciate that. Please let me know if you come across any issues.

Elle is inviting you to a scheduled LU Zoom meeting.

TOPIC: Interview with [REDACTED]

WHEN: Dec 7, 2022 12:00 AM Stockholm (11:00 AM GMT)

WHERE: LU Zoom meeting [REDACTED]

You can also join the meeting by entering the following information in the Join a meeting dialogue or in the Zoom app:

Meeting ID: [REDACTED]

The audio of the interview will be recorded - because of this I would appreciate it if you found a place where we are not bothered by unnecessary background noise or other disturbances. I will let you know before I start the recording and you have to agree before the recording starts. No one except me will hear the recording and when I am done with my thesis the audio file will be deleted.

As previously mentioned, the interview is centered around your experience with creating content about ADHD on social media. If anything is unclear during the interview, or if you don't feel comfortable answering a specific question, just let me know and we will move on to the next one.

I am looking forward to speaking with you soon \* and please don't hesitate to reach out if you have any questions or concerns.

All the best,  
Elle



## 2. Interview Guide

<p><i>Thank you so much for sitting down with me and talking about ADHD and being a content creator. I wanted to start with some general...</i></p> <p><b>(1) Questions about your experience with traditional media:</b></p> <ul style="list-style-type: none"> <li>- Do you think it's important with neurodivergent characters in entertainment like movies and television shows?</li> <li>YES - Why do you think that's significant?</li> <li>NO - Could you elaborate on why you don't think it's important?</li> <li>- What do you think of the representation of characters with ADHD in movies and tv-shows?</li> <li>→ Can you think of any good examples?</li> <li>- What is the worst example of ADHD you've come across?</li> <li>→ How did that make you feel? Why does that stand out in your memory?</li> <li>- Is there a stereotype or a pre-notion of ADHD that you are really tired of seeing or hearing about?</li> <li>→ Gendered stereotype, old, outdated research about the disorder</li> <li>- How do you feel about ADHD being described as a "superpower"?</li> <li>→ Do you agree with it?</li> </ul>	<p><b>(2) Questions about being a content creator:</b></p> <ul style="list-style-type: none"> <li>- When did you start your Instagram account and what was the biggest reason?</li> <li>→ Why did you choose Instagram?</li> <li>→ Changes to the platform</li> <li>- Do you create content on other platforms as well?</li> <li>→ Have you thought about using or incorporating other platforms?</li> <li>→ What are the reasons you use them?</li> <li>- In your posts, have you noticed if certain topics, or highlighting certain aspects of ADHD, perform better than others? In terms of likes, comments, and engagement</li> <li>→ Does this impact the content you post? In what way?</li> <li>- Are there certain topics you make an active choice in highlighting?</li> <li>- Lately, I have seen a lot of articles and debates about misinformation about ADHD on social media – especially TikTok – how do you feel about this?</li> <li>→ Do you think that this impacts how you create and present your posts now; do you feel like you are under extra scrutiny?</li> <li>- How do you manage the relationship between producing educational content and still learning about the disorder?</li> <li>→ Has this ever resulted in you deleting a post?</li> <li>- When you're creating content are you making a conscious effort in, for example, the language you use in your posts, to stay away from certain stereotypes or stigma?</li> <li>- Is it important to you to incorporate humor, or lighthearted aspects, in your post?</li> </ul>
<p><b>(3) Questions about the relation and interaction with others:</b></p> <ul style="list-style-type: none"> <li>- Do you often come across misinformation on Instagram?</li> <li>→ Examples? → What was your reaction? → Have you ever called someone out?</li> <li>- Have you ever seen anything that you consider to be very harmful?</li> <li>- Did you follow other accounts on Instagram about ADHD before you started your own?</li> <li>- Have you built any close relationships with other creators on the platform?</li> <li>- Have you ever been in a conflict with another creator on the platform?</li> <li>- <i>In my research about the representation of ADHD in other mediums, like articles in newspapers and magazines, I've come across a lot of debate regarding the medicalization of the disorder and whether or not it's a good or bad thing – is this debate something you see on social media as well?</i></li> <li>- On your account, do you have to deal with a lot of negative comments or skepticism?</li> <li>→ How do you do this?</li> <li>- As your account grows, and you can reach out to more people, do you feel more hesitant to share more personal experiences?</li> <li>- What is one of your most memorable interactions you've had on the platform?</li> <li>- In your own words, how would you describe the ADHD community on Instagram?</li> <li>→ Do you consider your followers and the people who interact with your content to be a part of this community?</li> <li>- What are some of the hardest challenges about maintaining your account?</li> <li>- What are some of the more rewarding aspects?</li> </ul>	<p><b>Personal</b></p> <ul style="list-style-type: none"> <li>- How old were you when you got diagnosed?</li> <li>- When did you suspect that you might have ADHD?</li> <li>- How was the experience getting your diagnosis?</li> <li>- Did you receive any comments or assumptions in your personal life after you were given your diagnosis?</li> <li>- Do you have a separate profile on Instagram for personal use?</li> <li>- Cultural differences</li> <li>+ <b>ADHD COACHING</b></li> <li>- How long have you been a coach?</li> <li>- How far in between starting your account and becoming a coach?</li> <li>- Good/Bad Aspects?</li> </ul>