



Munchausen By Internet

A VoiceBox report



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Introduction

At VoiceBox, we work hard to amplify the voices of young people around the world. We believe it is important to listen to and facilitate the debates young people are having – even when the topic is a difficult one. Our content platform provides a space for young people to talk about subjects that matter to them; from lighthearted trends to more serious issues.

In September 2021, we started to receive submissions from young people discussing how harmful it is for people to ‘pretend’ to have certain disorders on social media, such as Tourette syndrome, autism, obsessive compulsive disorder (OCD) and dissociative identity disorder (DID). We discovered that this is a phenomenon that a small group of professionals were also concerned about. It is a growing issue and is causing real concern to other young people with diagnosed disorders, or challenges they are dealing with that are causing them distress.

On social media, we have seen hashtags such as #touretteschallenge, #faketourettes, #didchallenge and #autismcheck gaining popularity with millions of views, increasing by the day. This issue may also be representative of an increase in cases of a fairly new mental condition.

Munchausen by Internet is a term coined by Dr. Marc D. Feldman and is defined as “when a person fabricates or exaggerates a physical and/or psychological ailment online. They do it primarily because it is gratifying to get other individuals to respond with sympathy and nurturance.” Different from Munchausen Syndrome, in Munchausen by Internet, an individual’s medical deception lives only (or primarily) in the virtual realm.¹ While most of the Munchausen by Internet cases that have been previously documented involved individuals falsely claiming to have *physical* ailments such as cancer or epilepsy, recently, we are seeing more and more individuals coming forward online to admit that they feigned a mental condition.

We acknowledge that this is a difficult and complex debate. No-one wants to suggest that young people are simply faking concerns about their health – particularly not when so much important work is underway encouraging more open discussions about mental health and wellbeing. But the fact that young people are actively engaging with hashtags with the word ‘challenge’ and ‘fake’ shows that young people are purposefully pretending to have these disorders, and that we appear to be seeing the emergence of an (as of yet) unrecognised mental health condition.

Introduction

Whatever the reasons, there is clearly an issue that is growing and being played out on social media.

Additionally, we are by no means saying that every young person who falsely portrays themselves as having a particular disorder fits into the category of suffering from Munchausen by Internet. However, we cannot ignore the correlation between what we are seeing online and the symptoms of Munchausen by Internet.

We decided to unpack this concern by discussing it with young people across the world, as well as professionals. Our aim is to understand what is going on and why.

Find out more about VoiceBox: <https://voicebox.site/>

We would like to give special thanks to:

All VoiceBox ambassadors who took part in this research. We wouldn't be where we are today without such a fantastic group of young people based in over 20 countries who are willing to share their thoughts and experiences.

Marc D. Feldman, M.D.: Clinical Professor of Psychiatry and Adjunct Professor of Psychology at the University of Alabama. He is the author of five books, including *Dying to be Ill: True Stories of Medical Deception*. He is the world's foremost authority on Munchausen by Internet.

Jonathan Baggaley: Jonathan has been Chief Executive of the PSHE Association since September 2016. He was previously the Head of Education at the Child Exploitation and Online Protection Centre.

The Mix: The UK's leading digital youth charity, supporting over 4 million young people each year through our helpline, counselling service, online resources and moderated peer community. We are there to help under 25s take on any challenge they are facing, from mental health, money and homelessness to break-ups, drugs and finding a job.

Royal Mencap Society: is a leading charity aiming to improve the lives of individuals with a learning disability and their families. Mencap wants to make a significant and measurable improvement to people's attitudes toward people with a learning disability.

Methodology

This report describes the emerging trend of faking disorders online, as well as an increase in potential Munchausen by Internet cases and an increasing understanding that is a genuine condition and not always individuals looking to scam others online.

This report also explores why young people are participating in this behaviour. It examines what the implications might be for young people in our digital spaces, and offers suggestions about what might be done to respond to such a complex phenomenon.

Our findings are based on discussions with our network of international ambassadors and online research via opinion-gathering platforms such as Reddit and Twitter. Finally we conducted a literature review that was inevitably limited given the newness of the issue. We also conducted one-on-one interviews with a number of experts based in the UK and the US. We are hugely grateful for those who took part in this research, especially given the sensitivity of the issue.

All statements from young people have been anonymised to protect the identity of those involved. Unless noted otherwise, we have also decided to anonymise quotes from those experts who participated in this report.

Context

Young people are increasingly using social media to discuss their experiences of disorders such as autism and Tourette's. This has been fantastic for raising awareness, and has allowed young people to gain a sense of community by connecting with their peers and sharing their experiences.

"TikTok is like a form of therapy. If I just speak about [my health] to as many people as possible, it feels less scary." – a young person

"We have ambassadors who have disabilities who like to go out and talk about their disability because they understand that they can advocate for themselves and others who have those disabilities. They are advocating for the fact that they can do more than what people often give them credit for. They want to be in the conversation and be at the table." – Mencap

Unfortunately, over the past year, we have seen a new trend on social media. One that involves young people pretending to have such disorders. Whilst this behaviour is easy to dismiss as odd but harmless, VoiceBox contributors tell a different story. They describe negative implications for people who have a diagnosis, and harm for individuals participating in the trend who subsequently suffer online backlash as a result of being "outed" for faking.

It is easy to imagine that this is a niche social media oddity, limited to a short term trend that will disappear as so many other strange digital fashions have in the past. That may still prove to be the case – but in the meantime we are seeing a significant number of young people claiming to have different disorders online, particularly Tourette's, autism, OCD and dissociative identity disorder (DID) with no such diagnoses. This phenomenon is predominantly – but not exclusively – on TikTok, with hashtags such as #touretteschallenge (4.9M views), #faketourettes (1.8M views), #didchallenge (2.3M views) and #autismcheck (16.1M views) racking up millions of views.

The following examples describe what happens.

Context

1

Tourette's Syndrome

Young people film their tics and post them on social media; including head or shoulder jerking, touching objects repeatedly, facial grimacing, vocal outbursts, and jumping. However, this is a syndrome that can easily be exaggerated for comic effect, and Tourette's experts have said that some of these videos do not accurately portray someone with the disorder.

At the beginning of 2021, the British Medical Journal noted that doctors at Great Ormond Street Hospital reported a significant increase in adolescents portraying tic-like symptoms, particularly by teenage girls – despite Tourette's being much more common in boys.² Many have attributed this to be an anxiety response to the pandemic, but there is also debate around TikTok's direct role in this. While the normalisation of Tourette's can result in people recognising subtle symptoms in themselves, it might also encourage individuals to imitate the behaviours they are exposed to on social media.

2

OCD (obsessive-compulsive disorder)

People with OCD often have frequent obsessive thoughts and compulsive behaviours.³ They try to lessen anxiety surrounding those obsessions with coping mechanisms including repetitive actions or thoughts, compulsive checking, hoarding and counting – to name but a few. OCD often causes distress for those who have it and can interfere with their normal lives. Young people, and even middle-aged adults, are showing off their immaculately clean and organised homes on TikTok, using the hashtag #OCDcheck (69 million views). These videos will also often use the sound clip of Hollywood socialite Khloe Kardashian saying, "you say OCD is a disease, I say it's a blessing". However, there are lots of comments and other videos arguing against the idea of the disorder being a "blessing". They explain that the symptoms that come with having serious OCD are far more debilitating than the romanticised versions that get shown in many TikTok videos.

Context

3

Autism

Young people are filming themselves showing symptoms of autism. One of the most popular formats is for people to show themselves “stimming to music”. “Stimming” refers to self-stimulating behaviours, usually involving repetitive movements or sounds.⁴ However, stimming isn’t always an accurate representation of autism. Additionally, many would argue that autism isn’t a “syndrome”, but simply a different way of thinking. Depicting the act of stimming in an exaggerated way can harmfully portray those with autism as intellectually vulnerable, and puts them at risk of feeling alienated from society.

“It is hypothesised that this unusual presentation is related to lockdown, change in usual structure and routine, social media related events/bullying and pandemic-related stress in vulnerable adolescents. Stress may be unmasking a tic predisposition in some, while in others compounding existing vulnerability to anxiety, for example, underlying neurodevelopmental or emotional difficulties to the point of becoming overwhelming.” – an expert

4

Dissociative Identity Disorder (DID)

Dissociative identity disorder, previously called multiple personality disorder, is usually triggered by traumatic events during childhood such as physical and/or sexual abuse.⁵ The brain responds to these harmful memories by distancing or detaching itself from them in order to lessen the effects of the person’s suffering. DID is characterised by the presence of two or more distinct personality identities called “alters”.

Each alter is likely to possess a unique name, personal history and set of characteristics – ranging from interests, to age, to sexual orientation to gender. In combination, alters are called a “system” and co-exist in the “head space” – the DID term for brain. Alters can “switch” to take over the body at any time, also known as “fronting”. It is common for alters to have roles within the system such as the host, protector, trauma holder, and caretaker.

Context

4 contd.

Despite DID presenting itself as an extremely rare disorder in the offline world (affecting between 0.01 and 1% of the population), the hashtag #did on TikTok has over 1.4 billion views.

A popular format of video for those in a system is to catch themselves “switching” on video and to do alter introductions (a video portraying each of their personalities and their characteristics).

Another phenomenon we have identified in the course of our research is the presence of “fictional alters” (aka fictives). “Fictives” are alters that are based on fictional people or characters. These characters can be from movies, television shows, books, video games, and other forms of fiction. People who claim to have fictives in their systems will often dress in clothes and makeup that make them look more like that character. And often, videos will be captioned as “we are a system, not cosplaying.”

There is controversy, even within the DID community, surrounding the legitimacy and validity of fictives in DID systems. Some people believe that fictional alters are fake, and cannot occur in a real DID system. Others believe that fictives exist, but only within certain limitations. Finally, there are those who argue that all fictives are real and valid and should be treated the same as any other alter.

Despite the continuing debate surrounding fictives, some people suggest that the lack of scientific research and data into DID means that we can't truly know all of the symptoms that are linked to the disorder – fictives or otherwise – and how that same lack of scientific research and data means we also don't know people suffer from it. Whatever the outcome of those debates, we share our audience's concern about the proliferation of this behaviour online.

Online Responses

The digital community is quick to respond to these kinds of videos. The following section explores the most visible reactions.

Reddit and “fakeclaiming”

A lot of skeptical social media users have taken to the comments sections of TikTok videos, as well as other online platforms such as Reddit, to call out those that they believe are faking disorders online. Many faking disorder subreddits have hundreds of thousands of users, including: r/fakedisordercringe (176,000 users) r/didcringe (19,000 users) and r/illnessfakers (91,223 users). There are also many YouTube channels popping up that compile videos of those who they believe to be faking these disorders, labelling them as “fake disorder cringe compilations”. The act of calling someone out for faking a disorder has been dubbed “fakeclaiming”.

There is a lot of tension between “fakeclaimers” and other content creators, especially those arguing that you don’t need a diagnosis for your disorder to be valid. To add to the controversy, some creators later post videos admitting that they faked their disorder for “entertainment”. Others claim that they suffer with mental illnesses such as depression, and as a coping mechanism they tried to find comfort within other communities – even if their condition is different than the one portrayed. The latter situation describes key symptoms of Munchausen by Internet.

Some argue that it is crucial that the “fakers” get called out and this has led to cyberbullying and harassment online. Not only has this affected those who are feigning the disorders but it also has a damaging impact on those who genuinely have them, as they often get “fakeclaimed” as well.

Why are young people doing this?

Discussions with experts and our ambassadors – including some who have engaged in this phenomenon – pointed to lots of reasons that might explain why young people are doing this. Without more research it's only possible for us to share their ideas which are based on their understanding either of their peers or as experts in their field. If it is the case that some of the people engaged in this behaviour are suffering from Munchausen by Internet we are observing the emergence of a mental health condition that is not just amplified by the internet – it is caused by it.

1 Depression and Loneliness

Despite being more connected than ever, young people can often feel more isolated from one another. Alongside this, the global pandemic has heightened feelings of isolation and loneliness for individuals around the world.

“People are more isolated than ever. They need to feel belonging and they want to feel unique” – a young person

When someone is accused of ‘attention-seeking’ there are usually deeper issues that are causing such behaviour such as a low sense of self-worth or depression. These feelings can appear at any time in our lives, but it's important to recognise how challenging life can be in your teens and twenties, as well as the range of ways in which someone might respond.

“I don't think that those faking are 100% okay or perfectly healthy people because no one who is fine does this. In my experience, it was fueled by depression, dissociation, self harm, loneliness, being a stupid kid, and other issues I don't wish to mention.” – a young person

“I was a depressed kid who struggled with self-harm, and during that period in my life, I felt like I couldn't turn to anyone” – a young person

Many young people seek solace within online communities and form relationships with people around the world. While this provides many opportunities such as shared cultures, education and devoted friendships, young people will often try to connect with one another through shared experiences – whether real or imaginary.

2 Identity Struggles

It's common for young people to explore who they are and create an identity for themselves. While it's natural for adolescents to explore different identity traits and interests as they develop and grow, we are witnessing a new wave of behaviour being played out online on a much larger scale.

“Questions of identity and adolescent identity and how that takes place on social media are the first things that come to mind when I think about this issue. Some of the dynamics of teenagers wanting an identity or a group are probably manifesting here” – Jonathan Baggaley

Many young people felt that the disorders mentioned in this report, can be seen as 'quirky' and therefore an attractive identity trait.

“People have latched onto the idea of a mental illness as 'quirky' and something that makes them different from others” – a young person

Others argued that some people who are struggling to find their identity might choose to align themselves with certain disorders in order to create a sense of purpose and receive support and compassion.

“For people who lack a clear sense of self, being a “patient” provides them with a sense of purpose. Also, people are more likely to show them leniency to their usual responsibilities, and to provide them with acceptance and sympathy, all of which is appealing to individuals who are struggling to find themselves” – Dr. Marc D. Feldman

This effect is only exacerbated by the constant exposure to the countless online identities people may or may not have. In much the same way as an astrologer may use vague language and open ended questions that can create a strong identification with a star sign, online identities can 'infect' internet users through suggestion. While someone may not align with an identity originally, a simple relatable internet post can sow the seeds of a burgeoning, albeit superficial, identity. While it may seem trivial on the surface, a post conflating OCD with orderliness can open the door to the embrace of this new identity. This is a phenomenon that spans topics far beyond the scope of faking disorders, however it may serve as a part of the solution of why this trend is occurring.

3 Self-diagnosis and Misinformation

In today's digital world, it's easy to find information on anything you want. Just a few minutes of online searching and you can feel fairly confident about a specific topic. In a medical context, this means that anyone can research symptoms and view information about complicated subjects on a very surface level, rather than understanding the bigger picture by listening to doctors and professionals.

"People are self-diagnosing. For example, someone who might get nervous from time to time might claim that they have a serious anxiety disorder" – a young person

"Some people might not fake DID. They probably think they have DID. Those are two different things, and there's no shame in being misinformed." – a young person

Furthermore, we are seeing an increasing number of people discussing their disorders online. On the one hand, this is great for raising awareness, but on the other hand, much of the information out there can be misleading or incorrect. This results in many young people falsely diagnosing themselves with a specific disorder without understanding what that might mean for them in reality.

"I researched everything I was feeling, which eventually led me to DID. The actual disorder I struggle with is depression, and I have suffered through actual dissociation. I think I always knew deep down that I was faking it, but at the time it was a label that I thought worked for me. If people said I was faking, I got very angry because who were they to say I was wrong?" – a young person

While most people visiting virtual support groups are honest, everyone must balance empathy with circumspection. One should be especially careful about basing their personal healthcare decisions on uncorroborated information supplied on the internet. – Dr. Marc D. Feldman

Self-diagnosis is not always a bad thing. There are examples of people who have recognised symptoms in themselves from watching videos about the disorders outlined in this report. But it is important for them to then seek a proper diagnosis from a doctor in order to receive the correct support.

4 Entertainment Value

Unfortunately, many young people are mimicking symptoms for humour. This is especially apparent with disorders that can be exaggerated for comic effect, such as DID, Tourette's and OCD.

"There are definitely people who make these videos for "entertainment purposes"- a young person

"DID and Tourette's symptoms are sometimes dramatic and can be comical. So if the goal is to get the biggest audiences possible, elements with those characteristics would help" - Dr. Marc D. Feldman

"Unfortunately it's believable that people would fake having Tourette's after watching videos of people with Tourette's and thinking that it is funny or quirky or fake the tics to get attention." - a young person

"I've seen people claiming to have alters that are demons and fairies. People joke that no one has a straight man alter called "Dave", it always has to be something creative and fictional" - a young person

For example, you often see young people pretending to have Tourette's and showing exaggerated symptoms. According to Tourette's experts, these are not an accurate portrayal of someone who genuinely suffers from the disorder.

However, others have spoken about the benefits of portraying their disorder in a comical way as a coping mechanism.

"I used to use humor as a coping mechanism/escape from the pain. Finding the funny side helped lessen the power it held over me" - a young person with OCD

5 Internet Anonymity

Some young people who have faked a disorder online said that they would never do this in person, but that portraying disorders on social media was easier due to the ease and anonymity of doing so. The behaviour of faking has become more common as people feel confident to portray themselves differently to how they would offline.

“It’s so much easier to fake these things online – in real life, you can’t fake things like this constantly. Online, people only see a short 1-3 minute snippet of you and so you only have to keep up the act for that short period of time while filming” – a young person

“Faking disorders and illnesses is not a brand new concept but the opportunity to seek attention and nurture it through tech is new, Munchausen by Internet is more common than Munchausen syndrome” – Dr. Marc D. Feldman

“I feel like when you’re online you put on a persona so when you’re online you feel like you’re a lot more untouchable or people from your “real life” won’t see these videos so you can act differently online to access another community and feel like you fit in somewhere. Being online gives you more confidence to do those sort of things” – a young person

“When they have all the information freely on the internet it becomes much easier to capitalise on the situation.” – Mencap

There are fewer consequences in the online world as it’s easier to be anonymous and remove yourself from a situation if you were to get caught out.

“It was only online and no one has seen my face, so it hasn’t come back to bite me.” – a young person who faked having a disorder online

Internet Anonymity (Continued)

“If you slip up or make false claims you can find different groups and find a new network, which makes it impossible to track. Optimistically, you can find support elsewhere and recognise this problem and connect with others who are doing similar things” – Dr. Marc D. Feldman

As many of these disorders mentioned are ‘invisible’ it becomes easier for many to get away with pretending to have them as it’s harder for others to challenge them.

“It’s easier to fake some of these things because they are “invisible” disorders such as learning disabilities and autism – there are no physical symptoms on the body that need to be displayed” – Mencap

6 Romanticisation

Over the last decade, awareness, understanding and acceptance of mental health issues has improved significantly. Young people are more able to open up about their health and receive the support they need. Clearly that is a very positive step forward.

Progress has been supported and facilitated by many people in the public eye who openly discuss their disorders and mental health issues. One such celebrity is Billie Eilish, who has openly discussed her Tourette’s diagnosis. Whilst this is fantastic for raising awareness, some young people who idolise her are now ‘romanticising’ and copying her tics. This becomes problematic when people who are suffering with the disorders – including Eilish herself – see others pretend to have the symptoms that they suffer with on a daily basis.

*“I think it’s because of the romanticisation of mental illnesses in the media”
– a young person*

“It’s almost cool to be mentally ill now. It started with depression and anxiety but then those became too popular so people turned to more extreme and rare disorders such as DID and Tourettes” – a young person

7 Naivety

This romanticisation of disorders seems to come from a place of naivety and lack of understanding of what it is actually like to live with them.

Understandably, young people who actually suffer with these disorders might not feel comfortable sharing their struggles openly and certainly carry no responsibility to do so. As a result, the majority of the videos we saw didn't accurately portray the reality of the conditions.

“I suffer so much from OCD and I'd never do a quirky video about it” - a young person

It's also easy to forget about the implications your actions might have on others. Some young people seem unaware of the harm they are causing.

“This is part of teenage naivety. We aren't always going to understand the seriousness of some things. The difference is now we have the internet to broadcast these things out. Once it's on the internet it's there forever and is viewed a lot more than it would have before.” - a young person

“There's going to be a lot of naivety, especially if we are not teaching about it in schools. They might think that it's ok to copy these things that they see online”- a young person

“During primary school and high school there were lots of people boasting about how they had “OCD”. Back then I didn't know as much about mental illnesses as I do now so I just accepted it. Now I know more so I have a better understanding of it and so I know its not cool to make fun of it or romanticise it”- a young person

8 Financial Gain

Worryingly, some young people appear to be pretending to have certain disorders for financial gain. There have been prominent cases of influencers – such as Belle Gibson⁶ – who have pretended to have serious illnesses such as cancer in order to popularise their business and benefit financially. Whilst extreme and unusual, some of the young people we talked to believed that, in some instances, people were identifying with these disorders to stand out and gain notoriety.

“I saw a YouTube video that was proving that someone was faking Tourette’s in a comedic way on Tiktok. She used the fake Tourette’s to try and gain attention to her online business. She would present tics in some videos but often did long live streams and didn’t present Tourette’s so she was able to switch it on and off when it was beneficial to her”- a young person

Is this actually new?

Normal Teenage Behaviour

Perhaps this trend is nothing new. Identifying the difference between normal teenage behaviours and a potentially new condition like Munchausen by Internet is the job of professionals. However some have brought up the fact that this behavior could simply be a continuation of normal behaviours around teenage angst and the feelings of being misunderstood and different as you try and work out who you are.

What starts as a simple stationery interest at school can become a serious enthusiasm and that in turn might lead a young teen to a feeling that they have a symptom of OCD. Teenagers have always obsessed over fictional characters such as Edward Cullen, and now we see young people portraying a fictive alter who *is* Edward Cullen.

Many of the young people we talked to expressed how dramatising one's life is common teenage behaviour that has simply been amplified online.

However, others argued that it was something much more extreme and problematic.

Whether or not it is simply an amplification of normal teenage behaviour or a new internet specific condition, the fact that it's become such a phenomenon is damaging and problematic.

"It's definitely not normal teenage behaviour. Fangirling is normal. This is way too extreme. Faking disorders is not normal behaviour and it is harmful for those who actually have the disorders" – a young person

Is this actually new?

Just Another Trend?

There are huge pressures on young people to gain popularity online and portray the best version of themselves. Many people (adults included) would admit to displaying a different version of themselves on social media, rather than the reality.

Some people felt that faking disorders online is part of 'trend culture' and trends can be amplified by social media as these platforms are designed to be attention-grabbing and trend-based.

"The very nature of TikTok is fast and trend-based designed to grasp your attention." – an expert

However, others believe that this is something much bigger and more problematic than a common trend with serious, negative implications.

"With online personas, we subconsciously know they are fake and there have been trends to remind us that often the personas we see online are fake such as the "Instagram vs reality" trend. Faking disorders shouldn't be a trend. It's not just an online persona. It's something that's becoming a habit and it's not acceptable. It is not acceptable to make fun of or pretend to have those mental illnesses" – a young person

Others suggested that simply calling it a trend was problematic, as it isn't just about popular culture and taking part in the latest social media movements. Instead, there are much deeper concerns that need to be addressed.

"I find it so surprising that it has actually become a trend. You can't tell whether people are being real or fake about it especially when it comes to serious disorders. So I think this is worse. Even if they don't have the disorder they are faking they still need help because there is probably something underlying that needs to be worked out that is causing them to fake these disorders" – a young person

What does this mean?

The purpose of this report is to raise awareness and articulate an issue that worries our VoiceBox audience. The fact that it has come to us as an issue to explore is enough for us to be concerned. But it is well beyond the scope of this report – and clearly outside our expertise – to offer an assessment of the implications. What we have seen, and know to be happening is that young people are being exposed for ‘faking’ their disorders predominantly on platforms such as Reddit and YouTube. This can have enormous consequences for anyone who is singled out, and anyone who worries they might be targeted in the future particularly if it’s something they regret having done.

1 The Impacts on Those Who Suffer With These Disorders

We heard heartfelt reports from young people with disorders. They expressed anger and sadness at seeing content from people pretending to have disorders that they have to cope with on a daily basis.

“Do these people on TikTok even know what it’s like to actually have these disorders? It’s not fun or cute, it sucks so much” – a young person

“I’ve seen so many people who claim to have autism without a doctor’s diagnosis. Just because they have a “weird interest” or “enjoy certain parts of a song”. Videos of them ‘stimming’ to stuff is infuriating because that’s such a glamorised part of autism that’s considered “cute”. This is one that particularly grinds my gears as autism can shut so many people off from society and disadvantage them.” – a young person

“These people have these lifelong conditions which can consistently create barriers for them in all aspects of life, so I think they would be appalled that people are out there trying to falsely portray this for followers” – Mencap

The Impacts on Those Who Suffer With These Disorders (Continued)

We found that many young people with these disorders are actually reluctant to speak about them online due to negative experiences in the past and the reality of living with such disorders. These false videos only serve to create a greater barrier for those actually suffering with these disorders.

“A lot of our young people are on social media but they don’t often use it for talking about their disability as they might have had negative experiences in the past” – Mencap

We have also been told that some people who suffer with these disorders no longer feel comfortable to speak about it, as they fear being mocked or accused of lying.

“It’s really damaging to the people who actually have those disorders because more people will question whether or not the people who have it are faking or not.” – a young person

“I suffer from anxiety and sometimes my panic attacks can be debilitating. But I keep my anxiety a secret from most people because I’m afraid it won’t be taken seriously or people will think that I’m flaunting it for attention. I am so desperate to not be grouped into the attention seekers” – a young person

“I am concerned about the impact on people who have disorders to tell their story in their own way” – an expert

“It’s causing a lot of toxicity on the internet between fakeclaimers and the content creators. People with genuine disorders are being attacked now.” – a young person

Finally, we heard that sufferers felt that their experiences had been devalued due to accusations of people ‘faking’ the disorders that they were dealing with.

“It really does not sit well with me. It makes people throw around terms like anxiety and depression and panic attacks when that’s not really what they are experiencing. It severely weakens the meaning behind those words” – a young person

The Impacts on Those Who Suffer With These Disorders (Continued)

“Think of the harm it brings to real people who will be ignored because people (with no idea what they're talking about) call them liars simply because they don't fit their uneducated opinion of how a mental illness looks.” – a young person

“It dishonours people's actual experiences. Is the way to destigmatize mental health issues to make them look like fun, when they most definitely are not?” – Jonathan Baggaley

Others said that even though they recognised symptoms in themselves, they didn't seek actual help as they didn't want to be accused of lying or 'jumping on a trend'.

“I don't know if the "tics" are real, or if I've been socially conditioned or something to display abnormal behaviour. If my tics get worse after reading the article, does that mean I'm subconsciously imitating symptoms of Tourette's?” – a young person

“What does this do to the people who actually have the disorders and are afraid to speak up?”– Jonathan Baggaley

2 Cyberbullying

A clear thread that ran through all of our investigations into this issue was the ease with which this could lead to cyberbullying. Accusing someone of faking a disorder creates a new space for bullying, which is obviously deeply harmful and unpleasant. Our VoiceBox contributors tell us how important it is not to leap to judgement. Professionals are discovering new patterns of behaviour within mental health illnesses and disorders all the time – no diagnosis is static and can't be treated as such. Nor is it possible for any casual consumer of content to form any real judgement about whether someone's claims online are real or fake when it comes to mental health.

"We have a tendency to put our best selves online. Maybe they have all the messy symptoms and don't show, because who wants to be around that? The successful accounts are the ones who present themselves as embracing the disorder, the quirky parts that we can laugh at. It's human nature to avoid pain; these accounts make people feel like they too could learn to live with it." – a young person

Those who are accused of 'faking' a disorder might have other issues they are facing in their lives. The action of calling out and harrassing social media users is deeply unhelpful and can have hugely negative ramifications for that person.

*"As long as they aren't spreading misinformation, it's not a bad thing. These kinds of people aren't getting special treatment in real life, that's for damn sure. But in the end, we're all people, and for all we know the hair-dyed, hand flapping autistic teenager could be going through daily sh*t at school and feel ostracised from their peers." – a young person*

"The problem with people harassing those who have faked these disorders is that they just see that this person is faking a disorder and don't look at the bigger picture that there are probably some underlying issues that are causing them to do this" – Mencap

3 Can 'Faking' Raise Awareness and Educate?

Some of the young people we spoke to felt that this type of social media content – fake or not – can still have a positive effect by raising awareness and educating people on such disorders. They argued that it can help break down stigmas and allow people to feel more comfortable to discuss their experiences and connect with others similar to themselves.

“It does suck that it's been turned into a trend of sorts, but on the other hand I feel like it raises awareness of how different autism can be for everyone. I think that if awareness is being spread and more people are getting diagnosed I don't view that as a bad thing” – a young person

A few were able to recognise symptoms in themselves after watching these videos and, upon seeking professional help, were given a formal diagnosis.

“I watched a few videos from people with autism and I realised I related to the criteria and was professionally diagnosed a few months later on.” – a young person

Conversely, many argued that the negatives around misinformation and the volume of those being exposed for being deemed 'fakers' outweigh any potential benefits.

“Even though they are bringing more attention to these disorders they are also causing a lot of speculation about who is faking it and who is not. Once it is exposed that a person was faking the disorder the focus becomes whether or not other people who are presenting these disorders are faking or it or not when that shouldn't be the focus.” – a young person

“It can be really destructive and delegitimize the progress that can be made in areas surrounding these disorders when people learn that the information is false” – Dr. Marc D. Feldman

Can 'Faking' Raise Awareness and Educate? (Continued)

"It should be the people who actually have the disorders who are giving out the information rather than people who are "acting". When people are faking it they often show the romanticised version of it – they only show snippets of it rather than the whole picture that might show a much worse reality of what having the disorder is actually like" – a young person

Others challenged whether these videos do actually break stigmas, and argued that, if anything, they can often create more.

"Videos of people comically portraying autism just further fuels the stigma that people with autism are weirdos. It's not funny or cute, it's literally just a different way of viewing the world. Can't people just leave it at that?" – a young person

"Does it break down stigma? Does awareness presented through TikTok actually break down stigma? Let's say some of them are watchable, intriguing, or comical, is that helpful in breaking down stigma? Especially if it is a fake presentation of a really complicated disorder that can be presented in all sorts of ways." – Jonathan Baggaley

Many felt that despite the right intentions, these videos on social media were not the way to raise awareness and break down stigmas. Social media has the potential to have an enormous positive impact, yet used inappropriately the consequences can be hugely damaging.

"It feels like there is a line between raising certain issues in a manner that demonstrates respect and dignity but then not exploiting these issues for entertainment " – an expert

"I can kind of understand that some people are faking the disorders because they are trying to "educate" people on the topic but even if the intentions are good that's not the way to go about it at all because it harms the people who actually have it." – a young person

"The harm is outweighing the opportunity right now. Social media can be an important place to tell your story in your own words but the misuse can create spaces which become toxic" – an expert

How should we respond?

1 Tech Companies

As this is a trend that is appearing on social media platforms, it feels reasonable to expect tech companies to bear the weight of responsibility. We see a need for social media giants to investigate the current climate and to help protect young people from harm, whether it be from distressing content or cyberbullying. We would recommend a review of moderation processes in order to lessen the impact of potentially harmful content – although we recognise how technically challenging that would be. Distinguishing between genuine accounts and fake accounts is obviously very difficult.

“This isn’t happening that often in real life so you have to attack the problem at the source which is the social media platforms” – a young person

“Are the social media systems themselves incentivising content to be quickly entertaining and not challenging misinformation in the way they should be?” – an expert

“The context of the online safety bill in the UK will put obligations on social media companies. There are active questions about the role of moderators as well as codes of conduct and principles on how we treat each other online. What should people do if they see content that upsets them and want to challenge it? How are schools or support mechanisms supporting young people to navigate these issues?” – an expert

Our audience recognises the complexity and is equally alive to the need to protect free speech.

“I think that telling social media apps to delete accounts that are faking it still presents the problem of trying to differentiate who is faking and who isn’t. It’s too hard to tell so it’s better if those platforms were able to spread the message that it’s not ok to fake mental illnesses online and educate people about the harms around it. Supporting those who actually have it” – a young person

Tech Companies (Continued)

“I think TikTok should do something about it but I’m not sure they can. It’s not like they can take down every video about a disorder” – a young person

“There is a line between censorship and appropriately recognizing information. You don’t want to censor people but you need a healthy scepticism” – Dr. Marc D. Feldman

2 Education

Perhaps the most important task is to improve education and information. There is a lack of awareness of this topic and a real nervousness about discussing it. This reluctance to discuss it leaves young people uninformed. Many who have participated in this phenomenon subsequently expressed regret at their behaviour and were hugely apologetic for the harm that this may have caused to others.

“The people who participate in trends like these are mostly young people who don’t have the maturity needed to realise that such mental illnesses are painful, real, issues, and I do think as they grow up a bit they’ll be horrified at their trivialization of a marginalised group’s struggle” – a young person

Finding ways to discuss unpalatable trends is – we would argue – the absolute responsibility of people with the knowledge and maturity needed to do so sensitively. All of the young people and the experts that we spoke to thought it was essential that these conversations were happening in schools.

“In schools, we need to talk about disorders more in the curriculum because that will reduce the number of teenagers that go online and fake disorders” – a young person

“While there is an important role for schools to play in taking these harder conversations, I think we need to understand the role of complimentary support. Whether it’s peer support or groups exploring what it means to be a digital citizen – sometimes these informal conversations can offer alternative safe spaces where young people can bring up stuff that they wouldn’t feel comfortable talking about normally.” – an expert

Education (Continued)

“We should embed it into a wider programme within PSHE that tackles subjects like: When to seek help? How do you talk about disorders? What stigmatises? What doesn’t help?” – Jonathan Baggaley

However, in order to create a meaningful impact, education needs to go beyond schools and should include educating young people at home and within local settings, such as sports and youth clubs. There needs to be greater collaboration between youth services, both educationally and medically, in order to support young people.

“You can’t tackle something like this from one perspective – it has to be multi-faceted” – an expert

“In high school PSHE when people came in to talk to us, in the short term it would be effective but people would quickly forget about it. It might be best to have a serious group discussion in class. You need a follow up to continue the conversation. It could also be a club whether in school or outside of school to allow for further discussion” – a young person

“Formal institutions are not keeping on top of these trends, young people are having to educate themselves on it.” – an expert

“There is a need for collaboration between paediatric and mental health services”. – an expert

As well as speaking to a doctor, we should encourage young people to reach out to free and confidential services, such as those at The Mix, to talk through any worries they might have about their mental health.” – The Mix

3 Understanding and compassion

This report is very much a starting point. We need to explore this issue in more depth to gain a greater understanding of what is going on and how we can support young people around the world. We are challenging others to be brave enough to discuss the undiscussable.

“It needs to be talked about more so that we can educate young people. Exposure of this topic needs to be created.” – Mencap

We need to explore the issues affecting young people to better understand why they are behaving this way online.

“I don't know how desperate you have to be to use a mental illness as a personality or an identity just to get famous or to have some kind of acceptance. I think these people also need help, and not just because they are faking mental illnesses, but because they are also causing huge damage to themselves, not just to their followers. These people need to understand that they are worth more than that.” – a young person

“We mustn't underestimate what's going on in these young people's minds or underappreciate some of the underlying problems. We have been through a once-in-a-generation or even lifetime pandemic and lockdown and there's more pressure on young people than ever before.” – an expert

The online world moves incredibly quickly, and the phenomenon of what we are witnessing now will evolve, and new 'trends' will inevitably appear. We need to equip young people with the resources and knowledge to respond and recover appropriately. It isn't good enough for the world's policymakers and global tech companies to be having conversations that are rooted in yesterday's problems and last year's understanding.

“The digital world is only ever the magnification of the real world. We need to consider the context of these young people's mental health and how they are expressing themselves and trying to explore their identity. We need to get better at listening” – an expert

4 Greater Support and Recognition of Munchausen by Internet

Finally, we are calling for greater support and kindness to be shown to those who are self-diagnosing, or suffering from Munchausen by Internet as this is more often than not a very challenging and confusing experience.

“We should let young people know that it's really important to practice kindness when it comes to others who are self-diagnosing. Although a mental health condition may be self-diagnosed and therefore not necessarily reliable, this can feel real and scary to the person in question, and if they are called out on social media or made fun of, it might feel very hurtful.” – The Mix

“If it is systematic of a different mental health issue, then that is important that educators know how to respond to that. If I am a teacher, and I find out that my pupil is doing that, then I need to have the resources to know how to handle that situation in the best way possible. We need to raise awareness about this issue so that we can come up with appropriate ways to handle it” – Jonathan Baggaley

It seems like many people are keen to talk about the mental health issues that social media causes/amplifies when they are issues that we have a better understanding of, such as anxiety and depression. However, not many people are willing to discuss these emerging and less understood conditions that are being kindled by the internet.

“Usually when you get to the actual root of the problem (usually depression or anxiety) those individuals who suffer from Munchausen by Internet will stop feigning disorders online. Those feigning the disorders also deserve to get the help they need.” – Dr. Marc D. Feldman

Greater Support and Recognition of Munchausen by Internet (Continued)

Furthermore, some psychologists have been advocating for years that Munchausen by Internet to be formally acknowledged in a revised version of the Diagnostic and Statistical Manual DSM-5, so that individuals who suffer from it can be diagnosed and treated for it more effectively.⁷ Thankfully, there have recently been some great steps towards this goal. The newest version of DSM-5, called DSM-5-TR, came out in March 2022. This new version doesn't use the Munchausen by Internet term, but under the heading of Factitious Disorder, it does say in the text that Factitious Disorder can occur in real life, online, or in a combination of real-life and online. However, an individual must represent a severe enough pattern of behaviour to justify the factitious disorder term, and the goal must be intangible (e.g., nurturance, sympathy, attention, or control of others).⁸ We hope that there will continue to be steps towards properly recognising this disorder.

“There's been very little study about Munchausen by Internet, so no one knows how big the phenomenon is. It's also hard to validate, as not many people have studied it from a clinical perspective.” – Dr. Marc D. Feldman

Conclusion

We hope this report has surfaced some of the complexity of this phenomenon.

It is designed to help kick-start a much needed conversation and raise awareness on behalf of young people around the world. We are actively encouraging further research by psychology professionals and emphasize the importance of having Munchausen by Internet properly acknowledged so that the people suffering with it can get the help that they need. We are also encouraging for this phenomenon to be looked into by the tech companies themselves and by the policy makers who are creating and discussing policies on a daily basis – often divorced from the reality of young lives online.

We appreciate that this is a difficult topic to discuss. However, we often see organisations talking about having “open conversations” about the challenges young people are facing, yet when we tried to reach out to organisations to discuss this topic with us many shied away from it. It was discouraging, as we feel young people’s challenges can’t be helped if no one is willing to even talk about them. We hope to see – and, through this report, inspire – new conversations throughout the coming decade. And we urge that young people aren’t merely consulted in these conversations, but invited to lead them.

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