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Understanding Ethnocentric Judgments and the Impact on Autistic People:

A Trauma-Informed Foucauldian Discourse Analysis (TIFDA)

Katherine Uher

THE FOREWARNING

There has been much contention within the very varied autistic community about what it means to be ‘really autistic’. Somewhere on social media someone made a comment that stuck with me. I can’t remember what platform, the name of who said it, or even the exact words they used to express the idea. And I suspect it has been said many times by many people anyway. The statement is along the lines of, ‘anyone who can speak articulately about autism doesn’t have the kind of autism I’m interested in.’

I think, rather than spend time trying to prove I have ‘real’ autism I would be better off just giving in and making a different point altogether. I *don’t* have the type of autism everyone is interested in. But most ‘autism researchers’ don’t have autism *at all*. Also, I am not researching and writing about a single ‘type’ of autism. I am exploring the way in which autism in general is often misunderstood and how that affects us regardless of where we sit on the spectrum.

Over the past four years, and with great enthusiasm, as I fully believed this to be exciting stuff, I have been reading sections of my thesis to my husband, a lecturer of marine chemistry. He would listen quietly as I shared my research. Not unlike how I would listen as he told me about the importance of photochemistry for global biogeochemical cycles, trace gas emission in the North Sea, or the rising plankton levels in the Indian Ocean.

Unlike me - when I read to him - he would offer feedback.

‘Kate, PhD dissertations are meant to be *dispassionate*.’

My husband is one of those ‘evidence-based’, natural science types. I am not.

I am a social science researcher, and when I began this research, I was invited to inject art and creativity into my work. Here, in this work, ‘art’ is a heavy use of italics, personal anecdotes, the occasional ‘bad’ word, and a reference to unauthorized drug use. Also, I like starting sentences with conjunctions. It makes me feel rebellious.

ABSTRACT

In the past decade, the prevalence of autism diagnoses has seen a significant increase. Alarming statistics reveal that autistic individuals face a disproportionately higher risk of suicide compared to the general population, with intelligent adult women experiencing an even more pronounced vulnerability. Prevailing pathological discourses often attribute such distress to the victims' cognitive processes, perpetuating a pathologizing, deficit-based narrative rooted in research conducted by non-autistic individuals, labelling the autistic way of being as a disability that leads to suffering.

This thesis examines how the judgments made by non-autistic professionals concerning autistic service users, and the subsequent treatments and service adaptations delivered, are grounded in a deep-seated and often invisible cultural bias and how they induce stress, vulnerability and trauma in autistic people. The research process integrated a range of methods to gather a set of textual resources to analyze this theme and challenge the existing pathology framework. Priority was given to data collected from autistic individuals and their families. Methods included drawing on the author's personal experiences and her work as a psychotherapist, in-depth interviews with four adult autistic research participants, dialogue with the published memoirs and blogposts of autistic adults and activists, and critical analysis of the portrayal and 'treatment' of autistic people in mainstream health, education and care communications and practices.

To analyze the collected textual data, a novel research method called Trauma-Informed Foucauldian Discourse Analysis (TIFDA) was developed. Inspired by Michel Foucault's ideas on discourse, power and knowledge, the researcher expanded the Foucauldian framework to incorporate an appreciation of the harmful emotional impact of discriminatory practices, developing a trauma-informed approach to discourse analysis.

For My Son

Special Thanks to:

Seamus & Fiona

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PART ONE: WHY THIS RESEARCH

CHAPTER 1: THE SIDEWAYS TREES

I sometimes ask myself how it came about that I was the one to develop the theory of relativity. The reason, I think, is that a normal adult never stops to think about problems of space and time. These are things which he has thought of as a child. But my intellectual development was delayed, as a result of which I began to wonder about space and time only when I had already grown up (Einstein, 1949: p. 435).

When walking in the woods with my children, we usually find that most trees grow more or less upwards. This is typical tree development. But occasionally, to our great delight, we find divergent trees, with branches low to the ground, growing sideways. I do not think these sorts of trees are ‘developmentally delayed’ – they can be large and magnificent in their own right. They have simply developed in their own direction and in their own way. However, if the groundskeeper kept coming along and chopping the trunk back when it grew sideways or deprived it of nourishment, to ‘encourage’ normative growth, it might well become ‘developmentally delayed’. This would be sad, because it might have been such an amazing tree if it had been allowed to grow into what it was meant to be—perfect for climbing or sitting on, perfect for being in the moment with. These ‘sideways trees’ are the artists, the inventors, the poets, the philosophers, the psychotherapists, or simply the people who remind us there is joy in simply *being*.

In this introductory chapter I will be highlighting my background, personal interest in this research, key terminology along with my underpinning ontological position.

MY BACKGROUND

In 1983 (age 6) I was diagnosed with Pervasive Developmental Disorder, later called Asperger’s Syndrome, before eventually being placed under the heading of Autistic Spectrum Condition. Growing up I was interested in understanding how my experience of life was different to those around me. Ultimately this led to my academic interest in psychology and a career as a psychotherapist. Before this, I held different jobs. In my late teens I worked as an orderly at a nursing home. In my mid-twenties I worked as a counsellor at a residential home for children. Between having my own children, I was a special needs teaching assistant. It was finally in my

mid-thirties that I started down the path of becoming a psychotherapist. I took jobs in these different fields for the same reasons many do. I wanted to help. I was a professional working within different institutions. These settings were rife with critiques of how the life of the individual should look.

‘Ms. Parker ate all of her dinner.’

‘The latency girls were all in bed by curfew.’

‘The students handed in their homework.’

Much less scrutiny was put on the institutions. The expectations simply... *were*. The work of being a private therapist felt different. I worked for myself. I could uphold respect for the autonomy of my clients. Neither of us was answering to an institution. My role was only to sit with and support the client. As a psychotherapist I felt as though I finally found my place in the world.

For my Master of Science in Psychotherapy I sought out and interviewed other autistic psychotherapists about how they experienced their psychotherapy training. My reason for this question was because I had found my training to help me make meaning of my past experiences. Having this cohesion healed something in me that lingered from early life experiences of having been Othered.

‘Othering’ refers to the process by which a group or individual is defined as ‘Other’ or different from the dominant group in a society. Theorist Gayatri Spivak (2007) used the concept of Othering in the context of colonialism and postcolonialism. It involved representing colonized people as primitive, uncivilized, and inferior to Europeans, and using these negative stereotypes to justify colonialism and imperialism. Many scholars have explored the concept of ‘othering’ in relation to power, identity and social hierarchies such as: Simone de Beauvoir (2022), Frantz Fanon and Judith Butler (2007) and Edward Said (1979), who discussed the construction of the Other in his influential work ‘Orientalism’.

The main theme that emerged from my MSc research was ‘understanding’. It was such a big theme (covering more than 85% of all content from the interviews) that I needed to identify sub-themes to break it down. The sub-themes included: (1) Past experiences of not being

understood.; (2) Fear of not being understood in the future; (3) Learning to better understand oneself after years of internalizing the perception of non-autistics; and (4) The positive psychological effects of making oneself understood by others.

Another finding that emerged from my MSc was that all participants now viewed their mental health as something separate from their autism. Autism was, for them, a way of processing information and engaging with the world around them, often experienced as a bombardment of stimulation and awareness. A hyper focus. A tendency towards direct or explicit communication. All of which could be problematic in the wrong environment. The participants had previously felt anxiety and anger were inherent parts of their autism but, having gone through years of psychotherapy training, they were all starting to see their anxiety and anger as something different from their autism. Like me they were seeing it as a response to experiences of having felt Othered and misunderstood by a predominantly non-autistic society (Uher, 2018).

I was fascinated with how much impact being properly understood had on one's mental health. It was the same for me but, prior to that research, being misunderstood had been such a big part of the unseen background of my life I had never considered how it had affected me. It was all the ways I deviated from the neurotypical majority (which I considered my faults) which stood out for me. What I mean by this, is for many years I simply understood myself through the stories others applied to me.

THIS RESEARCH

Following my MSc, I knew I wanted to continue my research at PhD level. And, *had my life continued smoothly in the direction it was going*, I would have asked the following question for my PhD research:

'How could therapists support autistic clients to better cope with the experience of being misunderstood by a non-autistic majority?'

However, this did *not* become my research question. In the Summer of 2018, as I was finishing my MSc, events happened that forced me to reconsider the emphasis I was putting on helping autistic people to cope better. I started questioning my own internalized bias that autism was

a flawed way of being. This was a painful process. It involved confronting deeply embedded fear and shame around demanding space to be different, have children that worked differently, and as such parent differently.

My new research question eventually became:

‘How is the wellbeing of autistic adults affected by the experience of ethnocentric judgments from non-autistic professionals within education, health and social services?’

Hugh Coolican writes about ethnocentrism, the tendency to judge others by one’s own culture. Coolican offers an example of this when he describes how Westerners who like to “greet with a firm handshake and full eye-contact” (2019: 225) might think Asians who prefer to bow and have no eye contact are shy. This view is filtered through the Westerner’s cultural understanding and fails to consider the Asian culture.

For the purposes of my research ethnocentric judgments have two parts which require attention as detailed below:

1. NEUROTYPICALITY IS BEST

Despite the fact that the benchmark for ‘normal’ is constantly in flux, the notion of normality in the now still has great power. As Danziger asserts it is “a power as old as Aristotle to bridge the fact/value distinction, whispering in your ear that what is normal is also all right” (1992: 160). This way of understanding ‘deviance’ creates foundational discourses on how we see people who deviate from social or institutional expectations, when deviating from the societal norms of the time are often viewed either as poor health, immoral or both. Behaviours that are not in keeping with the expectations of the dominant culture are often described in terms that suggest poor morality and choice such as ‘inappropriate’ or ‘refuses to engage,’ which I suspect many people find to be detrimental to their sense of self-value.

2. THE NEUROTYPICAL CORRECTLY UNDERSTANDS THE AUTISTIC

Much of the research around autism could not be examined through the necessary depth of knowledge required to explain what was going on inside for people with autism. To make such claims, a shared understanding of what it means to be neurotypical and autistic, a “shared

savoir”, (Foucault, 1972: 15) to use a Foucauldian term meaning “depth knowledge” (Hacking, 1995: 198) would be required.

In this work I compare such judgments and frustrations to cultural clashes. Autism is not a culture in the colloquial sense of the word, which implies being born into a group that is consistently socially connected, where norms are learnt through social interaction rather than ingrained in one’s neurology. Autism is not learned. However, I would argue that understanding oneself is learned- and this is done through our relationships with others- which is dependent on a shared understanding of experience. Relying on one’s environment for self-development is in line with its use by philosopher Marcus Tullius Cicero in his book series *Tusculan Disputations* (1472), as an agricultural metaphor ‘to culture the soul’. Continuing on with Cicero’s metaphor, when an individual does not have the proper environment in which to be cultivated, they fail to thrive. Like deviant trees which require trust and acceptance, autistic people often benefit from other autistic people to help with the self-actualization process- making autism a culture.

In the years since starting my PhD, new research looking at the intersection between autism, discrimination and trauma has emerged. A primary work in this area is *Neurodiversity Studies: A New Critical Paradigm* (Rosqvist, Chown and Stenning, 2020). This collection brings together a range of works exploring the concept of neurodiversity. Although not specifically about autism, the collection covers a range of divergent neurologies including autism, ADHD, dyslexia, Tourette's syndrome, bipolar disorder, and schizophrenia, among others. The authors provide critical analyses of the current state of research in these areas and offer alternative perspectives on how to understand and support neurodiverse individuals within society, education, and healthcare.

An overriding message from this collection is that the traditional medical model of viewing neurological differences as disorders or deficits is insufficient and often leads to stigmatization and marginalization. Instead, it proposes a neurodiversity paradigm that recognizes neurological differences as natural variations in human cognition and behaviour, which can have both strengths and challenges. Like ‘ethnicity’, the term ‘neurodiversity’ is often used incorrectly to (1) refer *only* to people with neurological conditions and (2) to describe people outside of one’s own culture. When we use the term ‘ethnic’ to describe someone, often we

are Othering them against a perceived non-ethnic group which does not actually exist (Coolican, 2009). All people have an ethnicity and are neurodiverse. I rely on the neurodiversity paradigm to inform the philosophical foundations of my research. Below I look at the origins of the concept of neurodiversity which will lay out some of the foundational theoretical concepts that underpin my research.

THE EVOLUTION OF THE NEURODIVERSITY FRAMEWORK

In 1976 the Union of the Physically Impaired Against Segregation (UPIAS) published a paper which was seminal in developing what would become known as the social model of disability. The UPIAS identified the term 'disability' as, "the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS, 1997: 35).

This work is regarded as the beginning of the social model of disability (Tregaskis, 2010), which was more firmly established by Mike Oliver in *Social Work with Disabled People* (Oliver and Sapey, 1999), where he locates 'disabilities' not with the individual who works outside of societal norms, but with a society which does not accept or allow for deviations to the norms.

Within the decade after Oliver's book came out, Judy Singer, a young autistic woman working on her honour's degree in Sociology at the University of Sydney, wrote her dissertation on neurodiversity. Singer's thesis "draws its roots from a social model of disability" (Kreck, 2013: 11) and uses it to make a distinction between the biological nature of autism and the social oppression experienced by people with a different neurology such as autism (Runswick-Cole, 2014). In line with the cultural discourse on autism, the neurodiversity movement recognized that people who are neurodivergent are the minority and experience ethnocentric judgments in the same way as other oppressed groups. Singer's thesis challenges the idea that neurological conditions are disorders and considers them as alternative ways of being, but maintains that they require a protected status in society by likening them to a social-political group like gender, race, or sexual orientation (Runswick-Cole, 2017; Singer, 2017).

In the early 1990's we had the Neurodiversity Movement, alongside the Mad People's Movement, which started in Brazil, Canada and the UK, seemingly as reactions to separate

events. But all shared the same root system, germinated by philosophers, critical thinkers, qualitative researchers, narrative researchers, critical race theorists, feminist studies, queer studies, hippies, anti-establishment folk, and the counterculture at large. Tended to by the collective unconscious of a society that rejected the tidiness of the authorised accounts of that which is 'ordered' and 'disordered'.

The Neurodiversity Movement raises awareness of societal prejudice against people with alternative ways of thinking and communicating (Runswick-Cole, 2014). But this leads to one of the main criticisms of the neurodiversity paradigm: it is perceived by many to deny that some neurodiverse individuals do suffer *from* their conditions and not simply societal prejudice. It may be that for some suffering is an innate bi-product of cognitive function. *But this could be true of people whether autistic or not.* I have met people with pronounced autism who seemed wired towards happiness regardless of the situation. And I have met neurotypical people who seemed wired towards misery regardless of the situation. Certainly, this challenges the assumption that autism is responsible for suffering.

Being autistic may mean that there are some things that are challenging for us that are not as challenging for the majority. These challenges may be disabling but they do not have to translate into suffering. In the words of Naoki Higashida, himself classified as being 'severely' autistic, "functioning in our society is difficult for neuro-atypicals, but encountering difficulties is not the same thing as being unhappy" (Waltz, 2020: 261).

Researchers Jo Renty and Herbert Roeyers (2007) found that quality of life for autistic persons was more likely to be determined by the type of support they received rather than the 'severity' of their autism. Other recent studies have shown that autistic persons with lower support needs ('higher functioning' autism) are more likely to be misunderstood by professional helpers and have a higher prevalence of suicide, three times higher than the general, non-autistic, population (Cassidy, 2020). In her PhD thesis, non-autistic researcher Kate Jenkins used interviews with autistic participants to look at the impact of non-autistic people's presumptions on autistic adults. She found that social marginalisation was the primary difficulty experienced by the autistic participants, with sensory issues being only a secondary concern (Jenkins, 2014). These findings are in line with my experience as a psychotherapist working with autistic clients.

‘WELLBEING’

In “The Challenge of Defining Wellbeing” (Dodge, Daly, Hutton and Sanders, 2012), researchers used a multi-disciplinary review to evaluate different theoretical frameworks through which wellbeing might be understood. At the end they propose a cumulative definition of wellbeing to be: An individual’s sense of balance, which can be impacted by life experience and the meeting or obstructing their physical, emotional and social needs. The underlined portions are the aspects of wellbeing I wish to emphasise.

Looking first at a sense of balance, I want to address that the term ‘balance’ might be too ambiguous; but if we understand this to be determined by the individual’s own self-assessment of balance, this becomes an effective form of measurement which can be kept in mind when reading the narratives offered by both myself and my research participants. Later, I will highlight terms or phrases my participants used which indicate an assessment of imbalance including: ‘snowball,’ ‘tailspin,’ ‘tenterhooks,’ ‘stumbling block,’ ‘*collapse on myself*’. The reader might identify more such terms and phrases as they read.

The Neurodiversity Paradigm relies on philosopher Elizabeth Barnes’ (2016) definition of wellbeing which is much the same as above - but in addition Barnes differentiates between ‘local wellbeing’ and ‘non-local wellbeing’. She considers local wellbeing to be our wellbeing in response to an impact, a certain time, space or situation. Non-local wellbeing extends beyond the temporary, creating an effect which lingers in our lives. Early on I was challenged when I used the words ‘impact’ and ‘effect’ interchangeably. To consider my research question - which seeks to look at the long-term *effect* on a person’s wellbeing - it is important to realize that a person’s wellbeing can be off-kilter in some *specific* ways but in general, still be level. I would add, this is particularly important when discussing groups of people considered to have psychological ‘disabilities’ which might be held responsible for a person’s overall wellbeing.

‘TREATMENTS’

The second underlined portion was regarding the meeting or obstructing of one’s physical, emotional or social needs. This is where helpers come in. In my research I look at the role of professional helpers in our lives. When referring to the ‘treatment of professional helpers’, I mean the professional’s behaviours, micro-behaviours (attitudes) and their intended interventions. This is to do with the perspective of the service user. In a professional context,

the term 'treatment' often refers to a chosen course of action meant to help another. However, in a broader sense, treatment can also mean our behaviour towards another person, as in 'our treatment of that person'. In this study, I use the term to mean both, as many would argue that anytime a person is operating as a professional helper, all behaviours are treatments which impact on the service recipient, intended or not. Regardless, it would be difficult to unblur the lines between actions as professional or social treatments, as many professional treatments are developed and informed by a neurotypical sense of sociality to start with. Ultimately this is about privilege - which groups get to decide what the aims should be and thus what 'treatments' are needed. This includes the treatments for parents and carers.

Blogger, SEND Parent Uncut (28th May 2021, Why separation comes from a VERY different place in autistic children) likens parents and carers of autistic children to well-trained auxiliary aids. The support provided for individuals with autism is extremely personalized, making 'universal' training or support very difficult. However, a child's parent or caregiver undergoes specific training tailored to understand and address the distinctive characteristics of their autistic child, a process refined over many years. Using this simile, when someone misuses an auxiliary aid such as a ramp or wheelchair to the point that it is breaking down, the individual who relies on that aid suffers for it.

The way parents and carers are treated in their role as advocates and protectors affects the wellbeing of autistic people. I would argue, it affects them perhaps most deeply because it seeps into their homes and most trusted relationships, altering what should be a sanctuary from the institutions. Eventually the heavy pressure placed on carers becomes another example of how ethnocentric judgments of professionals can impact on the well-being of the autistic person.

TROUBLING THE EDGES



Figure 1: Rubin's Vase / Faces

The image above is called Rubin's vase (or Rubin's faces) created by Danish psychologist Edgar Rubin for his doctoral thesis in 1915. The aim of this image was to make people consider the relationship between the figure they see and the background, which they do not see. Which part is the 'figure' and which is the 'background' is up to the individual viewer. This concept has become known as the figure-ground relationship. The figure-ground relationship could be understood as the juxtaposition between abnormal and normal- or the institution and the individual. We scrutinize one and often fail to notice or question the other. French philosopher Michel Foucault (Pronounced: Fuko¹) would call the unscrutinized background the 'normalizing truth' (Foucault 1977).

The Vases / Faces is a popular representation of figure-ground art, but there are other pictures which offer this same type of optical illusion. Once a person has looked at one such image and seen the trick (i.e., learned how to adjust their vision so that they might see the alternative image) that person will be able to see beyond other such illusions more quickly. For this reason, I make comparisons between different types of discrimination, so we might challenge our perception of current unexamined biases. In 1989, black feminist, Kimberly Crenshaw was the first person to use intersectionality as a methodological tool. Since then, her work in critical race theory has been used in feminism and queer theory and critical disability studies.

Throughout history, numerous scientists held the belief they had discovered tangible proof indicating that individuals of non-white descent possessed a lesser ability for logical thinking. The discourse that there was a biological foundation for male superiority over women has also endured for centuries. Propaganda opposing women's rights perpetuated the notion that women's intellect was inadequate for participation in politics or public affairs. This line of reasoning was used to exclude women from politics as a necessary 'safeguarding' measure. Mirroring such scientific discrimination is the claim that neurodivergent people are incapable of knowing their own minds or being entitled to make judgments about their lives or that any

¹ I was in my 40s when I first heard of the French philosopher Michel Foucault. I connected with his politics immediately. His name, not so much, although I sought to use his ideas in my research, I had to learn to pronounce his name! I wrote a cheat to myself: Fu-Ko. I repeated this every time I saw his name in print - eventually it sank in.

expressed distress is irrational. The way to manage the distress is to segregate them from mainstream society. Despite widespread recognition of *historical* acts of discrimination, similar acts against individuals with atypical neurology are still, dishearteningly, perceived as legitimate and simply ‘common sense’, making this form of discrimination the current unscrutinized background. One of the concepts I address in my work is the idea that *current* discourses are simply *normal* and don’t require scrutiny the way discourses of the past do. In other words, many people hold the view that ‘things aren’t as bad as they used to be’.

In order to critically examine the normalizing truths of our time we must first learn to see them. We must identify the edges of that which is the figure we see and acknowledge that there are silenced discourses in the background. Renee Echo Lodge, author of *Why I No Longer Talk to White People about Race*, says, “In order to dismantle unjust, racist structures, we must see race. We must see who benefits from their race, who is disproportionately impacted by negative stereotypes by their race, and to whom the power and privilege is bestowed upon” (2018: 45) In her book *For a Pragmatics of the Useless*, Erin Manning links neuro-based discrimination to race-based discrimination:

I see neurotypicality as akin to structural racism-as the infusion of white supremacy in the governing definition of what counts as human. The assumption that neurotypicality is the neutral ground from which difference asserts itself (2020: 32).

I am not seeking to compare marginalized groups to one another, or to say that as an autistic person I know what it is to grow up facing the same systemic oppression that people from other backgrounds experience. Each group has its own history and ways in which they are challenged by societal bias. I have been the recipient of oppression in some situations and privilege in others. It was never fair. To compare autism to race or sexual orientation would be wrong. What I am seeking to compare are the mechanics of privilege, discrimination and oppression such as: truth games, segregation, micro and macro aggressions, silent treatments, conversion therapies and gaslighting.

A UNIVERSAL TRUTH FOR ALL THE AUTISTICS I KNOW

In my psychotherapy practice I have worked with people who were diagnosed with autism in

early childhood, others in adolescence, and some in adulthood. Some have attended mainstream schools and others alternative provisions. Some have been non-verbal while others were extremely articulate. I have worked with those who are employed, those who are not and those who sometimes work but struggle with maintaining jobs. I have worked with those who have had romantic partners and friends and those who had none. And I have worked with those who lived independently, those who in their adulthood were still living with parents or those who lived in assisted living. I mention all of this because these are the details often used to identify how 'severe' or 'mild' someone's autism is. Without getting into a debate about whether it is right to use these details as markers, I can say there is a shared similarity in what my clients end up working on in therapy. Regardless of the above details, the work was always primarily focussed on healing from a felt sense of one or more of the following: (1) being a burden to others; (2) a fear of social rejection; (3) a fear of being 'wrong' in their way of understanding the world; and (4) shame.

What is also quite common amongst clients is that the autistic presentation has shifted a lot since childhood, and what is most stifling in their adulthood is often social anxiety, internalized oppression, a detachment from self and feelings of injustice that have never been legitimized by others. I have come to see my work with neurodivergent clients as being mostly about CPTSD (complex post traumatic distress)² from years of discrimination.

Regardless of how the *autism* affects the client I always feel that they would be better versions of themselves if they could let go of the lingering effects of the trauma they carry. This could be said about anyone, but when the individual we are talking about is neurodivergent, society tends to decide that any suffering is a result of their cognition - *they are just wired that way* – rather than to consider how 'challenging' traits might be a response to societal treatments.

MINORITY STRESS

Monique Botha and David Frost (2020) proposed extending the minority stress model to understand mental health problems experienced by the autistic population. Minority stress refers to the chronic stress experienced by members of stigmatized or marginalized groups due to discrimination, prejudice, and social exclusion. The minority stress model (MSM), initially

² CPTSD was coined by Judith Herman (2015) in her book, *Trauma and Recovery*.

used to examine health inequalities between LGBTQ individuals and the general population, has expanded its scope to encompass a broader range of populations. These now include ethnic minorities, individuals with disabilities, transgender and non-binary individuals, as well as immigrants and refugees (Golembe, 2021; Lund, 2021; Meyer, 2003; Pascoe, 2009; Testa, 2015; Valentín-Cortés, 2020).

Botha and Frost (2020) argue that autistic individuals face unique stressors that are not accounted for in the traditional MSM, and they propose that the autism-specific stressors, such as sensory overload or social isolation due to atypical communication and stigma, can lead to chronic stress and negatively impact mental health outcomes. Although Botha and Frost look at everyday discrimination, I seek to focus on iatrogenesis harm - which is harm that is done whilst receiving 'treatments' by professionals. This focus is inspired by personal events in my family's life which I share in Part Two of this work.

An important point to remember as you read this research is – as Dispensa (2017) asserts: Every experience - good or bad - becomes embossed chemically in our brains and bodies as a memory. Every experience develops into an expectation of what our future holds. Although this links to how we might understand post-traumatic stress, the body does not only remember the negative things. Our bodies are instinctively scared of fire, but our bodies also eagerly anticipate the pleasure of a favourite food. Our bodies remember low stimulating acts, such as tying our shoelaces or brushing our teeth, and are often able to perform such tasks on auto pilot. I want to make the point that being conditioned to expect a repeat of experience is a natural and unavoidable process - regardless of the nature of the experience we are remembering. Thus, low key stressors, not just big experiences, get remembered too. In line with this point, many trauma researchers would tell us that while most people think of trauma as an 'one-off' event, many traumas are actually "multiple, predictable and cumulative" (Afuape, 2011: 237). Such is the nature of discrimination for minority groups, whose bodies remember constant low-level experiences of invalidation.

LITERATURE

When looking for literature which would be relevant to my study, my first priority was to locate narrative research which looked at how ethnocentric judgments made by non-autistics

impacted on the wellbeing of autistics. To make sure I didn't exclude styles similar to narrative analysis such as interpretative phenomenological analysis, I looked through all qualitative works. My main criteria for literature was that it addressed the subject matter and it privileged autistic voices. There was a wealth of research about this, but- when I added in terms that might start to look at the *autistic person's* experience - this is when the numbers greatly reduced.

Anyone who has done a literature search knows that word choice plays a big role in the results which come up. The first search terms I used were: (Autis* or Asperg*) AND (bias or discrimination or prejudice or judgment or minority or oppression or power or stigma) AND (qualitative or narrative or interview*) I would occasionally hit blocks with terms like 'discrimination' which led to studies about choice making rather than prejudice. Another problematic term was 'trauma' which led to many results - but few where it was considered that the autistic person was suffering from trauma. Whenever I found a fruitful result, I combed through the references for anything that might be a relevant resource for my research until my literature results reached a point of saturation.

Very few were narrative based, and fewer relied on the voice of the autistic person. Instead, many looked at the stigma experienced by the families of autistic people but, as I've already mentioned, *not* the knock-on effect this had on the autistic person's wellbeing. I gradually narrowed my findings down from 2973 to 885 – and then to 22 – and then to 5 studies that looked at the effects of stigma on autistic peoples' wellbeing that met (1) an academic standard peer-reviewed article, (2) empirical research and/or (3) scholarship writing.

As an overview the gaps I found were in the following areas:

- A lack of exploration around what *leads* to autism stigma.
- A lack of focus on iatrogenesis harm.
- A lack of focus on how mistreatments to the family impact on the autistic person.
- How research is increasingly conducted by autistic people, but non-autistic research still dominates the field.
- How the Power Threat Meaning Framework (Boyle and Johnstone, 2018) has not been applied towards an understanding of autism.

Because I seek to privilege the autistic voice, I also bring in non-academic works such as books, blogs, social media posts and articles to support, challenge and contextualize my research. In order to present my research in a way that feels organic and engaging to me, I bring the literature into the research gradually throughout this thesis in the places where I feel it belongs rather than place it into a single chapter, as is often done.

SUMMARY

Prejudice, bias, and discrimination are often closely linked to hate, but it's important to recognize that discrimination isn't just something done by bad or hateful individuals. In essence, discrimination is about making choices and having preferences, and this is a fundamental aspect of being human that we all share.

Regrettably, the negative connotations of 'discrimination' have led us to resist the idea that we ourselves might have biases. Consequently, we deny ourselves the chance to reflect on the cultural messages shaping us and confront our unconscious prejudices. This lack of awareness perpetuates the suffering of others, unintentionally invalidating their struggles.

To foster a more compassionate and equitable society, we need to confront the fact that discrimination exists within all of us. I conducted this research and now write this thesis because I want to highlight that which hurts people that we have some power over. The primary works I will draw upon throughout my dissertation include *Neurodiversity Studies: A New Critical Paradigm* (Rosqvist, Chown and Chenning, 2020); “The Power Threat Meaning Framework: An Alternative Nondiagnostic Conceptual System” (2018), various works from Foucault (1982-2012) and ‘Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population’ (Botha and Frost, 2020).

For those who like a map of where we are heading, I have created the following outline.

The remainder of Part One explores what we think.
about differences and autism.

Chapter 2: LIFE, THE UNIVERSE, AND RESEARCH METHODOLOGIES

This chapter offers a deeper discussion about my methodological approach, methods employed and the ethics of activist research, as well as an opportunity to consider how we

know what we know.

Chapter 3: AUTISM'S BACKSTORY

Here we look at the clinical history of autism and how this concept was initially formulated by researchers who were not themselves autistic. This chapter offers a critical analysis of the deficit-based model and a genealogical overview of the historical development of discourses surrounding neurological deviations and perceived differences.

Part Two offers a reflexive engagement about
why the judgments of professionals are so impactful.

Chapter: 4 HELL: CIRCLE 9 ¾

In this chapter I explain the reason for this research and share a personal story which offers a deeper context for why this topic is important to me. I offer a reflexive engagement about internalized oppression and the complexities of the relationships between professionals and those they are meant to serve.

Chapter 5: 'OUR THOUGHTS ARE WITH THE FAMILY'

Following on from Chapter Three, this chapter is an extension on how professionals' ethnocentric judgments of autism can affect the autistic person through the family. To do this I offer a mix of my lived experience, existing research, interview material gained from a parent, and a general overview of my client work.

Chapter 6: 'LESSONS HAVE BEEN LEARNED'

In this chapter I take the genealogical aspect from Chapter Three and the acts of control seen in Chapters Four and Five and look at how these treatments have been reoccurring over decades. The title of this chapter speaks to the common statement we hear institutions make when abusive acts are highlighted, and yet they seem to persist often under new names or presented in new frameworks.

Part Three seeks to answer the research question:
How do ethnocentric judgments effect the wellbeing of autistic people.

Chapter 7 'BECAUSE I SAY SO.'

In this chapter participants have shared examples of feeling misunderstood by professionals who have held power in their lives. We start to see early glimpses of why this causes emotional harm to the individual.

Chapter 8 WE CALL THAT 'PRIVILEGE'

This chapter looks at the efforts the participants have made in their adult lives to assert their sense of self with professionals in their lives. This chapter touches on themes of invalidation, prejudice and homogenous discrimination.

Chapter 9 A WRONG SENSE OF BEING WRONG

Here the participants give in depth descriptions of the meaning they have made of being misunderstood by others and the instinctive responses that have arisen as a result to having their sense of self rejected by others. This chapter offers a compelling explanation as to why being misunderstood ultimately gets experienced as trauma.

Chapter 10 HEALING STRATEGIES

In this chapter participants share examples of what has helped them to heal and self-actualize, leading them to feel they are living more well-balanced lives. This offers a lot of what I draw from to create good practice guidelines.

Chapter 11 THE TRAUMA OF NORMATIVE BIAS

This chapter creates an overview of what the findings mean as a whole, and illustrates clearly and concisely the links between ethnocentric judgments and the effects on the autistic person.

Part Four is a summary of the research and a more focussed discussion,
on how professionals can improve their practices.

Chapter 12 HOW TO NOT TRAUMATIZE AUTISTIC PEOPLE

Here I offer a list of best practice guidelines with discussions on the need to practice ethical

bravery in environments that are not conducive to authenticity, as well as how we might go against traditional training methods.

Chapter 13 – TALKIN’ ‘BOUT THE ‘TISM’

Finally, I look at the implications this research has on future training and research as well as how I have made use of the findings to date to create a Trauma Informed Support Model (TISM) for working with autistic people.

CHAPTER 2: LIFE, THE UNIVERSE, AND RESEARCH METHODOLOGIES

'The Answer to the Great Question...Of Life, the Universe
and Everything... Is...Forty-two,' said Deep Thought,
with infinite majesty and calm
The Hitchhiker's Guide to the Galaxy (Adams, 2012: 45)

The quote I open this chapter with is one of my favourite quotes from my *favourite* book. The number '42' has become a shared joke with both my children, which we might offer up as the answer to any question at random. It always fits. Or rather, it almost never does. The point I was making with this quote is: The questions we ask are important but so are the *ways* in which we try to answer them. '42' seems to me to be a 'dispassionate' and unbiased response. But it is also totally ridiculous for the question being asked, which is about *the meaning of life*. My research question: '*How is the wellbeing of autistic adults affected...*' also, largely hinges on meaning.

Prior to starting my PhD, I saw research as something neatly contained: an activity one did only in academia. The more I got into my research project the more I began to realize that research cannot be separated from a basic human desire to make meaning or to explain one's sense of meaning to another. The reality is wanting to understand and be understood is simply the nature of people. People are conducting research all the time. Common research questions we like to ask are:

What is the meaning of life?

Am I normal?

Do you think he's cute?

In their book *Research as Social Change: New Opportunities for Qualitative Research* lecturers Michael Schratz and Rob Walker assert,

research is not a technical set of specialist skills but implicit in social action and close to the ways in which we act in everyday life, for we find increasingly that the worlds of academia and social life, theory and practice, work and family are not really so different but constantly interrupt one another, often in complex ways (1995: 2).

Descartes famously said, 'I think therefore I am' (cited in Beyssade, 1972). Inanimate objects do not think, question or explore. Another way of understanding this is: we cannot separate the act of questioning and exploring from having a state of consciousness. I also do not believe we can separate having a state of consciousness from having bias. It's my belief that all research is biased. The simple act of asking *some* questions rather than others demonstrates this. This research is a product of *my* bias and *my* desire to contribute to society in a specific way.

RECONSIDERING RESEARCH

My research explores ethnocentric judgments made by non-autistic professionals concerning autistic service users. One crucial ethnocentric judgment that significantly influences how professionals treat individuals with autism isn't directly related to the condition itself; rather it pertains to the way we acquire and trust knowledge.

It appears that professionals tend to prioritize 'evidence-based' research over lived experiences. This preference can lead to the dismissal of valuable insights gained from personal encounters and perspectives. In his groundbreaking work *A New Narrative for Psychology* Brian Schiff's (2017) challenges this status quo by reorienting our approach. He highlights a key objection to discarding the scientific method in psychology research, asserting that thoughts and feelings are considered abstract and difficult to reliably capture. However, it is essential to recognize that what we consider 'evidence' can often be influenced by unquestioned assumptions, including the definition of the standard way of being and whether it should be considered the ideal for all.

When certain ways of being are seen as the standard the research will work to reinforce this fundamental understanding. Foucault (2001) would argue that medical knowledge and practices are not neutral or objective but are instead shaped by current accepted discourses so that research is based on unquestioned assumptions (such as what constitutes healthy development) that seek to control and discipline bodies, particularly those that are considered deviant or abnormal.

I would argue that research which proposes to distil the human experience down to a number is highly unreliable as the emotional well-being of the participants are, as Holman Jones asserts “often disregarded in large-scale social scientific research projects” (2016: 23) and “the goals of predictability and controlling for error in quantitative analysis also can mean that research may lack nuance or even generate erroneous assumptions about social life” (2013 p.47). When it comes to social science the guesses don't get better by employing natural science research methods.

I make the declaration above that we are discriminating from birth. Another way to understand this is that we are making meaning of our perceptions from birth. In line with this, Boyle and Johnstone write:

This starts from the moment of our birth. Meanings shape our specific experiences as well as our general beliefs about the world. This is an obvious but crucial point. It implies that the same situation will be experienced very differently depending on the meaning it holds for us, which in turn will be shaped by the general power context. For example, having very little to eat will feel very different to someone who has chosen to go on a diet than it will to someone who has no money to buy food (2018: 56).

To explore my research question in a way which actively seeks to understand meaning, I asked four participants to tell me their stories of times when they felt misunderstood by professionals in their lives. I analyzed these stories for emerging discourses. I then looked at the effect their experiences were having on them and applied the Trauma Informed Foucauldian Discourse Analysis (TIFDA) which I created, to answer my research question.

Narrative researcher Jane Speedy notes that research modalities that question dominant discourse marry well with narrative research which seeks to help the reader see the world through “different eyes” (2008: 44). At the end of this work, I will offer a list of suggestions professionals can use to inform their own work, however, one of the best offerings might be in how we consider the information which informs our thinking. The ability to critically consider that which we are told is a living thing which can be taken with us into the different areas of our lives and applied over the course of our lives.

This chapter offers an opportunity for the reader to understand how I have applied the process of challenging discourses around autism and develop their own skills in this regard. In the next section I will discuss: (1) The ethics of activist research (2) My reasons and methods for using narrative inquiry (3) How and why I created the TIFDA method for analysis and (4) My recipe for applying TIFDA.

ACTIVIST RESEARCH

To ensure transparency and ethical rigor in my research, I am committed to recognizing the prevailing power dynamics between neurotypical (NT) and neurodivergent (ND) individuals. These structures often operate unnoticed and unchallenged in our daily lives. In Chapter One I wrote about not simply challenging societal norms of the past but reflecting on the present as well. The name ‘activist research’ implies activity / movement. It implies challenging the *current* way of thinking. I argue that all research aims to act and move something within society, particularly where the human sciences are concerned. As human science researchers we must challenge all current thinking and behaviours for legitimacy otherwise we risk producing research that is complicit in the current wrongs of society which cause suffering. We also risk not producing new knowledge or new ways of viewing human understanding. FDA researchers Kendall and Wickham (1999) highlight this as a potential hazard for researchers who don’t challenge current discourses but only identify flaws in historical discourses .

In both Feminist and Queer theory, research seeks to highlight something which may have been misrepresented in previous studies. Feminist research is the dual objective to contribute to the research topic at large while also affecting social change (Brayton, 2006). I consider that this objective is also an aim of queer studies. Because the researchers challenge current cultural views, neither paradigm seeks to remain neutral in its position. Similarly, on his Neuroqueer

website, Nick Walker (2014) comments that is not the remit of the neurodiversity paradigm to balance information with the pathology paradigm. He argues that “a ‘balance’ between right and wrong isn’t right; a ‘balance’ between good information and ignorant bigotry isn’t superior to good information”. Another way of understanding this is to understand that to remain neutral in certain matters inflicts further harm through the act of invalidating. A passage in the Power Threat Meaning Framework tells us:

Invalidation is sometimes visible or noticeable only when something is absent. For example, Western accounts of historical or recent events, including what is taught in schools and colleges, are often those of White men. Accounts by, say, women or non-Western groups may be presented as a ‘special’ perspective, leaving other accounts simply as ‘history’ or ‘reporting’ (Johnstone and Boyle, 2018: 137).

At the heart of my research lies the thesis that the process of Othering leads to emotional harm. It's important to note that I cannot assert this while remaining impartial. I firmly believe that maintaining a stance of 'neutrality' in the face of suffering perpetuates the process of Othering. In line with this perspective, I draw upon the insights of educational researcher Cassie Earl who notes that:

Merely reporting on the struggles of others with a supposed objective distance or joining unions to better our own terms of employment are methods that have been tried and tested for many years, and whilst these methods are important, we have watched conditions for all but the wealthiest few get worse (2017: 37).

I am of the conviction that openly incorporating my personal values and my aspiration for societal transformation into this research is of ethical importance.

EQUALITY IN RESEARCH METHOD AND PRESENTATION

This research relies on narratives from others and myself to examine the long-term effect normative bias has on autistic individuals. My use of the term ‘narrative’ should be understood to mean a story which has a beginning middle and end contained within a period in time. The reason I sought to use personal stories is the ease with which I feel they offer a nuanced understanding of experience for the reader as well as the accessibility of such stories. While

traditional academic writing is often criticized for being inaccessible and jargon-laden (Homan-Jones, 2012), life stories are often humanistic and relatable, presenting social science research in artistic ways (Speedy, 2007).

I also propose that by telling my story, alongside the stories of research participants, I am challenging the idea that the researcher or professional must be Other to those they seek to know. This seems appropriate when I ground my research in the thesis that much of what causes damage is the act of being Othered. The reality is that much of what has happened to my research participants has also happened to myself and my children. We are all human and the research I do with them I also do with myself. It is my belief that learning or researching without empathy is socially irresponsible and as such unethical. Morality is based on empathy and removing the human experience from the research means that the learning is based on numbers *rather* than a moral imperative to give appropriate care to the *people* we work for.

TIFDA

To analyze the narratives, I have created a research methodology called TIFDA, (Trauma Informed Foucauldian Discourse Analysis). Foucauldian Discourse Analysis (FDA) is a method of analyzing language and communication that is influenced by the ideas of Foucault. Discourse is a central concept for Foucault which is first introduced in *Madness and Civilization* (2001) but developed further in his later work. Discourses are a belief system we draw from. Some of the ways we communicate which discourses we are relying on is through our use of language, statements, treatments and non-verbal communications. Johnstone and Boyle make the following observations about how discourses impact our lives:

Discourses can create positive and negative identities or make it look as if some people deserve power and privilege more than others. They can make some experiences or social contributions invisible and some more visible and valued. They can make some claims seem like facts and hide their cultural roots. They can make some courses of action seem reasonable and justified and others seem unreasonable or even unthinkable (2018: 45).

I underlined the above sentence as I found this to be particularly relevant for research. At the outset of my research, I *only* used a Foucauldian Discourse Analysis (FDA) to examine hidden assumptions, values, and ideologies that underlie particular discourses on autism, and to challenge the dominant narratives that reinforce unequal power relations. Unlike typical Discourse Analysis which focuses on interpersonal communication, Foucauldian discourse analysis involves analyzing the language and practices of a particular discourse community to identify the ways in which they use language to shape perceptions, values, and actions. FDA looks at the availability of discourses within society and how they construct objects and subject positions within one's culture. It examines how these positions open up or limit opportunities for individuals, and how the discourses reflect and reinforce existing power structures offering a tool for understanding the complex relationship between language, power, and social change. It should be noted that I don't always wholly reject the discourses I identify. The issue I take with many discourses are the binary judgments which seem to emerge from them causing the individual and their experience to be missed.

Foucault sought to explain the relationship between knowledge, power, and social institutions. His works have raised awareness about how to look critically at current or past discourses to consider their legitimacy and question the norms of our time. His two well-known techniques for examining discourses are 'archaeological' and 'genealogical' discourse analyses. Archaeology discourse analysis acknowledges the current power structures and the discourses which are favoured at the time without judgment. Genealogical analysis involves considering why certain discourses are favoured, who these discourses serve and who they suppress and what is left silent (Foucault, 1989; Foucault, 2005). Considering what stories are not being told is also something Speedy (2008) notes is important in narrative research. And no doubt this question is raised by different people in different fields from journalism to crime solving. 'What is the question I'm not hearing?' is crucial for people who want a more complete perspective.

Foucault suggested that professionals in the 'psy' fields were responsible for causing deep states of distress similar to post traumatic stress disorder (PTSD) in service users (Foucault, 1996; Rose, 2020). However, Foucault did not focus on the nature of trauma or investigate the emotional impact of a fractured sense of self. As a result, using his theory alone did not adequately answer my question about the *effect* of discourses on autistic people. To look at the psychological impact of discrimination in my research I realized I needed to add in another

element to FDA which would allow for exploration of effect on well-being. To do this I drew from Lucy Johnstone and Mary Boyle's (2018) concept of the Power Threat Meaning Framework (PTMF).

The PTMF is a conceptual framework for understanding human distress and the ways in which it is influenced by social and environmental factors rather than solely by individual pathology. It was developed by a group of British psychologists and psychiatrists in response to the medicalization of human distress.

I call my research method 'Trauma-Informed Foucauldian Discourse Analysis' (TIFDA.) Aside from the research itself, the creation of TIFDA as a research method is my secondary contribution to the field of human sciences. TIFDA allows me to identify and explore discourses and power structures while also examining the emotional effects on individuals' well-being. This aligns well with the PTMF which suggests that psychological difficulties are best understood as a response to experiences of powerlessness, threat, and injustice, rather than as a result of individual 'mental health problems'³. It proposes that people's experiences of distress can be understood in terms of the ways in which they have been oppressed, marginalized, or deprived of power in their lives.

The PTMF is organized around four key themes: power, threat, meaning, and connection. 'Power' refers to the ways in which individuals are influenced by social, political, and economic power relations. 'Threat' refers to the ways in which individuals experience threat, harm, or injustice in their lives. 'Meaning' refers to the ways in which individuals make sense of their experiences of distress and their social context. 'Connection' refers to the ways in which individuals are connected to others, including their family, community and culture. The PTMF has been praised for its potential to transform mental health services by encouraging a more egalitarian and socially responsible approach to mental health care.

Because I draw heavily from the PTMF throughout my research, I would like to explain that it was not originally my plan to rely on the PTMF in my own research. Even after recognizing that

³ My quotation marks are not a reference, but rather I have used them because the PTMF calls into question how we currently frame the idea of mental health problems.

I needed a trauma informed approach, my research interest developed independently and my research, up to the point of write-up, had been done independent of me having read *The Power Threat Meaning Framework*. When I *finally* started reading this work by Lucy Johnstone and Mary Boyle (2018), I was surprised by how closely our ideas aligned - to the point that we often quoted the same authors both historic and contemporary. It evoked a strong feeling of validation. My reason for explaining this is to make the point that no one person has come up with the principles or ideas you will read here. Many individuals have come to these conclusions. I am one person, Foucault is another. Other researchers who share similar philosophical positions include Gabor Maté (2020), Judith Butler (2004), and Karl Marx (1968) to name only a few. I refer to many of these people at different times in this thesis, but I rely on the PTMF and Foucault to create my method for analysis.

Johnstone and Boyle clarify that the Power Treat Meaning Framework was not created to explain the *effects* of neurological conditions, and state specifically that *autism* has not been considered in their research. However, they do say that it may be used to explain the effects of the 'social consequences' of having such a condition, leaving this as a gap in existing research - which is precisely what I aim to address with my research.

I found that FDA and PTMF married well together because of their contrasting macro / micro approach to looking at the influence of power in our lives. Whereas Foucault takes a macro look at institutions and power, the PTMF take a more micro view of the individual's response to abuse of power. Foucault would say that the medicalization of mental health and the categories created to label deviance are an example of how institutions use power to support the ease of a functioning capitalistic society. The PTMF, agrees with this position, but also takes this further by calling out how such acts often *cause* human suffering whilst alleviating institutions of accountability:

More generally, diagnostic understandings can make our distress seem meaningless by cutting its links with our social contexts and relationships and focusing instead on what might be 'wrong' with our brains and bodies. This makes it easier to overlook the harmful impact of economic and social policies, negative life experiences or just taken-for-granted aspects of

everyday life such as gender-role expectations or working long hours (Johnstone and Boyle, 2018: 49-50).

The PTMF takes the view that emotional distress is caused by the individual feeling invalidated and makes the argument that recognizing (and validating) the person's experience is both necessary for healing wounds as well as societal justice. Beyond this, the PTMF & Foucault overlap in two additional ways: (1) both agree that mental health categories are based on social norms rather than science; and (2) an oppressive society *causes* the mental health problems people experience. Yet, neither Foucault nor the PTMF looks specifically at how people with neurological deviations are impacted by judgments of normality. As more and more people are receiving diagnoses of autism it is worth considering where do we fit into all of this? Part of considering this requires looking at the discourses that exist around autism at the moment. Which ones are silent? Which ones are in the background? And which ones are figure?

DATA COLLECTION

To answer my research question, I have combined a number of research methods: genealogy, critique of treatments, autoethnography and an interview-based project.

GENEALOGICAL ANALYSIS

Foucault's genealogical analysis is a method of historical inquiry that focuses on the development and emergence of various social, cultural, and intellectual practices over time. Genealogy, as conceived by Foucault, is a critical approach to understanding the complex relationships and power structures that shape the present. This method is particularly associated with his works such as *Discipline and Punish* (1979) and *The Birth of the Clinic* (Foucault, 2012).

In Chapter Three I use this method as I give an overview of mental health labels, looking at how and why they became important to our society and how they contributed to economic well-being in the Western world. I draw from features of Foucault's genealogical analysis which include: (1) A focus on power and knowledge - to look at how power operates in various social institutions and how knowledge of 'disorders' was produced and controlled by these institutions; (2) An exploration of historical context - to provide an understanding of the specific conditions and circumstances that led to the emergence of psychiatric discourses, and

clinical discourses in autism by looking at what was happening in Western countries before, during and after the time when autism started being used as a clinical label; and (3) Critical analysis of categories - I challenge the idea of medical categories and classifications of human differences highlighting that these labels are not only socially constructed and serve specific power interests, but they also change depending on the accepted discourse of the time.

In Chapters Four, Five and Six I examine micro-practices which focuses on small, everyday actions and local instances of power. By examining these practices, Foucault (1982) aimed to uncover the mechanisms through which power operates at the individual and societal levels. I find this is often played out by people who have accepted the institutional discourses of normality and what constitutes right or moral action without a critical understanding of the historical context to the discourses they are upholding.

In Chapter's Eight, Nine and Ten I show examples of resistance and agency demonstrated through my research participants. Foucault's genealogical method is not solely about oppression and domination, but also about how individuals and groups resist power and exert agency within the constraints of existing structures. This aspect of his work is evident in his concept of 'bio-power' (2012) and 'technologies of the self' (1982).

A CRITIQUE OF TREATMENTS

A critique of treatments refers to a systematic evaluation or analysis of various approaches, interventions, or methods employed to address a particular condition, issue, or problem. While Foucault did not focus specifically on critiques of medical treatments, his broader ideas about power, institutions, and the social construction of knowledge can be aligned with certain critiques within the medical and psychiatric domains.

Thomas Szasz (2014) challenged the concept of mental illness as a medical disease and was critical of the power dynamics within the psychiatric establishment. His views on the social construction of mental illness and the role of psychiatry in regulating behaviour are in line with Foucault's exploration of the relationship between power and knowledge.

Like Szasz, Johnstone and Boyle (2018) challenge the scientific validity of mental illness, asserting instead that it is subjective and based on societal norms, which stem from

institutional influences, rather than actual illness. I too continue with such critiques as I give a genealogical overview of autism and eventually demonstrate how such medicalized discourses become self-perpetuating as some researchers simply don't question the validity of the assumptions of what constitutes a disorder.

Szasz (2014) notes that in his work *Medical Nemesis*, Ivan Illich critiqued the medicalization of society and the overdependence on medical interventions. His ideas align with Foucault's examination of the ways in which institutions, including the medical establishment, exert power over individuals. These same themes start to emerge in Chapters Four, Five and Six as I look at how power associated, either directly or indirectly, with medical discourses is exercised over the individual. In these chapters I evaluate both the ethics and safety of such treatments including issues related to informed consent, patient autonomy, the potential for discrimination and the harm associated with such treatments.

In Chapters Seven through Ten my treatment critiques look at: (1) the service user's perspective, taking into account the experiences and preferences of individuals undergoing the treatment. Patient feedback and satisfaction are important indicators of a treatment's overall success; (2) The long term effects the treatments have had on the individual. Many treatments yield results desired by the institution such as compliance and silence, yet they can cause or create symptoms associated with post traumatic distress in the long run; and (3) Through the voices of my research participants alternative approaches are offered up for consideration to compare how different treatments by different professionals have had different effects.

AUTOETHNOGRAPHY

Autoethnography is a research and writing method which allows researchers to blend personal experiences with scholarly inquiry as it draws from the researcher's self-reflection and personal experiences. Autoethnographers use both personal narratives and analytical frameworks to explore broader cultural or social patterns. This allows them to move beyond individual experiences and make connections to wider social phenomena. In autoethnography, the researcher becomes a participant observer, actively engaging with the culture or context being studied. Over time autoethnography has been shaped by various influences and developments in the fields of anthropology, sociology, and qualitative research. (Holman Jones, 1985).

The roots of autoethnography can be traced back to the 1970s when anthropologists and sociologists started integrating personal experiences into their research. Scholars like Clifford Geertz (1973) emphasized the importance of 'thick description' and the researcher's involvement in the cultural context. While traditional ethnography involves an outsider studying a particular culture, autoethnography focuses on the insider's perspective, emphasizing the researcher's personal connection to the culture or context under study.

Once this method got its foothold this raised questions around objectivity and detachment in research. Is it necessary? Is it *possible*? For many the answer to the later question was no, for reasons I covered at the start of this chapter. Autoethnography started gaining momentum as scholars began to emphasize reflexivity, acknowledging the role of the researcher in shaping the research process and outcomes.

Autoethnography which had its roots in cultural studies lent itself well to research that sought to question social norms and challenge power structures, giving voice to marginalized perspectives. In the postmodern 1980's there was a rise in critical theorists such as feminist, race, and queer scholars, many of whom adopted an autoethnographic approach, advocating for the inclusion of personal narratives and subjective experiences. The rise of cultural and narrative studies in the 90s further contributed to the acceptance of autoethnography in the academic world although criticisms and concerns of the ethics of this methodology have always been topics of discussion.

Autoethnographers must navigate ethical considerations, especially when sharing personal and potentially sensitive experiences. This includes obtaining informed consent, protecting the anonymity of all parties mentioned, and considering the potential impact on both the researcher and others. Autoethnography recognizes the importance of the researcher's subjectivity and emotions in the research process. Emotions and personal experiences are seen as valuable sources of data and insight. But it is important to for autoethnographers to acknowledge and critically examining their own positionality, biases, and the impact of our personal experiences on the research process. This self-awareness is considered integral to the research.

KEY ETHICAL CONSIDERATIONS FOR MY INTERVIEW BASED RESEARCH

Key ethical considerations for all aspects of this study have been: (1) My commitment to use supervision to ensure my research was meeting ethical standards and academic rigor, as well as to offer a source of accountability for the following ethical issues; (2) Self-awareness and my responsibility to acknowledge the influence of my perspective on the interpretation of historical events and the construction of knowledge. I have sought to be aware of and transparent about my own biases and the limits to my competency which I hope will enable the reader to consider the weight they give to my research; (3) My cultural reflexivity. As I have tried to be aware of the challenges faced by marginalized groups in telling their stories and be sensitive to power dynamics, I have considered how intersectionality may affect participants' experiences and interpretations; and (4) Providing a clear balanced communication of my findings. To do this I have sought to clearly communicate my findings in a way that is understandable to both professionals and the general public whilst avoiding sensationalism and oversimplifications which could be considered essentialism which is discouraged when performing a genealogical analysis of complex histories.

I designed an in-depth longitudinal interview-based project, applied for and got ethical approval. I then started the recruitment process and gained informed consent from four research participants. Along with the general ethical considerations, there were additional ethical matters that needed to be considered and planned for with regards to the interviews and involvement of participants as I was mindful of protecting the emotional wellbeing of anyone I approached or who became involved in the study. I considered this from the earliest stages of the recruitment process, keeping in mind that autistic people often experience marginalization and acts of silencing or being misrepresented by others. As is standard with any interview-based project, I committed to offering debriefings and outside support if needed; but I felt that part of helping to ensure there was accurate representation of anyone who participated was to set up multiple interviews spaced at least one week apart to give the participants and myself time for reflection and clarification that I understood them correctly. However, in conducting a longitudinal study I needed to be mindful of the impact that in itself may have on the participants as multiple interviews are intended to facilitate deeper reflection and thus can give rise to reliving distressing events. I held this in mind when deciding who to approach to participate and I deliberately looked for participants I felt expressed an open interest in telling their stories. Finally, I took measures to ensure confidentiality of the

participants by changing their names and either leaving identifying details vague or changing them.

THE RECRUITMENT PROCESS

I chose to approach people rather than issuing an open invitation for people to approach me because I hoped to avoid having to turn people away and causing anyone to feel further invalidated as I imagined this was an experience many will have had throughout their lives. I did not know the participants I worked with in a deeply personal way. I met them in the following ways.

- One was met whilst doing quality control work for the NHS.
- Another was a mutual acquaintance of a psychologist I worked with.
- Another was an audience member who approached me following a talk I gave in London in 2015.
- The last was an author I met via a thread about autism on Quora.

After gaining consent from the Ethics Committee at my school, I sent out an email asking if they would be interested. The above 4 people responded, plus one additional person who later went silent. I understood either she became busy (she was moving house at the time) or decided she was not interested in participating in the research. It might also be worth noting that this person was worried about how local authorities might use the research if they found out she had participated as she was being accused of fabricated induced illness (FII) of her children. This is another ethnocentric judgment which disproportionately affects autistic people and their families. I write about this further in Chapter Six. To a person who has not been in her situation it may sound as if she was being paranoid, but there have been many cases in which local councils have combed through the social media accounts of parents they were in conflict with. I find it understandable that she would be worried.

THE PARTICIPANTS

Two of my research participants identify as male and two as female. Their ages ranged from 30 to 65 at the time of the research. I wanted to keep the number of participants small enough to collect and write up in-depth data but have more than a few participants in hopes of establishing shared themes across the narratives. I considered doing a group interview as

participants may have found listening to one another way to generate their own thinking and reflection on their experience, but ultimately, I decided that any shared themes might be more powerful because they came up independent of hearing the experience of others. This becomes a particularly salient point when noticing the language which in some cases was almost identical in describing experience. In one case I noticed that a participant was describing the experience of suffering they wished to impose on another, but in stating this their wording was identical to what the other three had used to express their personal experiences of suffering. I found it is highly telling that the understanding of suffering was shared whether it was expressed as felt suffering or imposed suffering. I interviewed each participant four times with the aim of asking four different questions and allowing space between each interview so that reflection could occur, and deeper layers could be explored.

I spoke with adults because I suspected adults would be better positioned to reflect on the effects of different experiences they had; and for ethical reasons, adults are better positioned to consider what information they would like to share as participants in a research project. But also, my goal was to look at the larger life impacts of ethnocentric judgments, and adults simply offered a better look at long-term impact on general wellbeing which can only be assessed when one has the autonomy to make their own life choices.

PERSONIFICATION

Every participant had their own voice, but the stories had many similarities, even some of the language used to express shared feelings was quite similar. That was wonderful in a way because these people had never met each other and to me this signified the very relatable experiences and feelings they all had. However, it also meant I needed to be mindful that their unique personalities could come through on the page.

As a side project I considered which of the four elements I thought they each represented. I felt that Jen was the fire element because of her confidence and warmth. I found Ziggy to be the wind element due to his fast and divergent thought process. Bob struck me as earthy owing to his calm and grounded character. Sarah, the archetypical therapist in my eyes, was the water. The more I could conceptualize their individual personalities the more I was able to create a persona that represented them without exposing their real identities.

I will refer to the four who participated as Ziggy (40), Sarah (35), Bob (65) and Jen (35). These are all pseudonyms, each name chosen for different reasons. I found that Bob reminded me of the painter Bob Ross. I found him to have a contemplative outlook on the world. Ziggy, with his cool outspoken spirit, tall slender build and long hair reminded me of Ziggy Marley from a concert I attended in my early twenties. Sarah had what I would consider to be stereotypical humanistic therapist qualities. She had a soft voice, her hair was unruly and she wore textured colourful clothes. Many therapists I knew were called Sarah, and she seemed to be the archetype of a therapist to me. I experienced Jen as being matter-of-fact and funny, as well as easily relatable. When I was young, Jen was such a common name that there were often 3 or 4 'Jens' in my year group at any time. I chose Jen's name to reflect this since I felt that she had an 'every woman' type of character.

To go with their names, I also chose font styles that, to me, captured each person's personality - as much as a font style can capture personality. I also note that I remain aware that all of this is filtered through my own perception of the participants. Whilst it is important to stay true to the words and the stories told, I had to give myself some permission to trust my intuition and perception of them as 'characters', in order that I could convey something of a real person to the reader.

We all agreed times to meet for roughly an hour on a weekly basis over Zoom to conduct the interviews. Once I had completed all four interviews for each participant, I was left with around 150 pages of transcript. Within those pages there were often repeats of the same story, sometimes highlighting the different aspects, an evolution of thought and understanding or simply an emphasis of what appeared to preoccupy each participant's thoughts.

In my research I have considered 'narrative' to be an account of a singular experience with a beginning, a middle and an end. With so many pages of 'bodies of statements' as it would be called in FDA (Parker 2010) I didn't immediately recognize the core stories for each participant.

As I will mention later in this work, I found Ziggy to be stepped back from and analytical of life as a whole. Using Ziggy as an example, after finishing our interviews I was left with an understanding of his ethos and overriding views on power and abuse of power, but identifying

and clearly understanding the events of his stories required me to return to the transcript a few times. I would end up doing this with all participants - sometimes to step back 'from the woods' in order to see the trees – and other times to delve deeper into the woods. I wanted to conceptualize each participant's main stories when I was no longer in front of the transcripts. This was crucial to the first part of my research question, which sought to understand the misunderstandings they had experienced, and then to use that as an anchor for the next part of the question which was about long-term effect.

This going into the transcripts and then stepping back from them was something I did repeatedly. As I started to feel I understood which stories each participant had brought to the interview, I began colour coding the stories so that I could more easily identify each time they were being referenced and start to bring these parts of the texts together. This allowed me to pull together the same stories across the pages.

At one point during this process, I had managed to get my entire family to leave the house for a week. My elderly mother and adult son went to America to visit family. My husband and teenage daughter went to Germany to visit family. And for that week I had the house to myself. I spread around 150 printed pages of transcript across the floor of our living room so that I could see the amount of colour visually representing each person's story. As they were told across multiple interviews the beginnings, middles and ends were retold across the interviews. After that I came back to the transcripts and began cutting down the text so that the stories were in one place. The seesaw of back and forth continued as I then looked sought to put the stories in order. Following that, I cut what I felt was unnecessary repetition, with a mind of keeping repetition that emphasized what the participant was saying.

I was first introduced to the concept of lyrical transcription by my supervisor who had used this technique. Following a reading from a medium who exclaimed that she could see me writing poetry and that I was quite intensely fixated on the project, I felt that this was a label of synchronicity that could not be ignored, and I began experimenting with this technique myself. I took a more macro approach to the lyrical transcription, allowing chunks of story to come through, rather than simply fragments of emotion which might be seen in other researcher's works. Upon reflection, because of the nature of my question and methodology, the chunks of

story were necessary. There needed to be enough information for context beyond the expressions discourse which can be interpreted from brief clusters of words and phrases.

I spent several months creating the poems and then, after I considered the poems finished, roughly a year later, I returned to the transcripts and sat down for several hours to reread each page. I did this for two reasons: one to confirm I had found the 'meatiest' themes to use in the poems; and two, to confirm that I had not missed something crucial. I was very nervous about reason two. I was a little nervous about the possibility of finding that I had developed tunnel vision over the past year and had spent a great deal of time discounting something crucial. To my relief I found this was not the case. I had left some stories out, for various reasons - often because they diverged too far from my research question - but I was happy to not find any surprises. And actually, surprised to not find any surprises.

AN IN-DEPTH LONGITUDINAL STUDY

The act of considering one's experience is a key feature in the PTMF which seeks to ask the following: (1) What happened to you?; (2) How did this affect you?; (3) What meaning did you make of this?; and (4) What did you have to do to survive?

As I stated, I conducted my research without being well acquainted with the PTMF, and so these were not the questions I asked, but interestingly there were some parallels which I think illustrates a universal understanding that these questions are important. My participants knew I was looking for stories regarding experiences they had with professionals in their lives. With that remit in mind I asked the following: In the first interview I asked: What story do you want to share with me? In the second interview: How did this affect you? (I note these first two questions are almost identical to the PTMF). For the third interview I asked: How did this change your life choices? (I find this to be a version of 'What did you have to do to survive?'). And for the final interview I asked: How has this impacted your expectations of the future? (which I consider to be in many ways linked to the meaning they made of their experience).

In keeping with researcher John Dewey's theory of continuity (1939) which is that a person's present-day experience is influenced by the past and will influence the future - I don't believe any experience can truly be isolated from others. The way we tell our truth is never fully free from cultural preconceptions. Foucault (1982) would argue that people are not truly free from the messages of their culture, but rather we create our narrative ('our' version of the story) within the accepted discourse, meaning it's not a totally autonomous story. This means we *can* struggle to know and tell our truth. I often find therapy clients will uncover a deeper level to their story in the time between sessions. It is often as if a layer of someone else's story has been pulled back so that the client can develop a more self-referencing account of their own narrative. The term 'self-referencing' is one I use to mean making meaning and judgments through one's own frame of reference rather than another person's. Being 'other-referencing'⁴ is a universal difficulty anyone can have, but I find it is far more prevalent in marginalized groups who have spent a lifetime having someone else's version of events applied to them.

⁴ Other-referencing is a term I will return to later in this thesis.

Additionally, for the autistic person who tends towards hyper empathy and symbiosis, time may be needed to reflect on and know their experience. As a way to support this process I tried to give the participants as much opportunity to think and reflect on their stories as I could whilst keeping momentum in the research.

At the end of Interviews One, Two and Three, I asked the participants to notice in the time between interviews whether the feelings that came up in their story were connected to feelings they encountered in other aspects of their life: 'Does the experience of feeling misunderstood by your primary school teacher remind you of other feelings of being misunderstood?'. My goal was not to ask them to do work between interviews. I simply wanted them to be open to noticing what came up in the week between interviews so that each participant might get as close as possible to their own meaning of their experience.

MY RETELLING OF THEIR STORIES

I have used the transcribed data from the interviews to create composites of the narratives to allow stories told over four interviews to be understood and be impactful in a shorter and more succinct format. For me, the composite process consisted of identifying the different stories each participant had shared and grouping the stories together. I ended up using a technique called poetic transcription which takes sections of the texts and combines them so that they tell the story in a succinct and impactful way. This technique was used by education lecturer, Kendall Jarrett (2016), in his paper *'Re-presenting teachers' experiences of game-based approaches through poetic transcription'*.

I initially began my analysis with an intention of using more traditional methods of presenting the narratives. The difficulty I encountered was that the emerging discourses were supported with statements that spanned across interviews from different weeks and thus large sections of text. An example was 'Sarah' who had shared a story about discussing her autism with her therapist. She retold this story in multiple interviews. I went through the interviews and grouped this story into a large portion of text. Following that I condensed the story down, taking out repeated details, although I would often leave in repeated words or phrases that felt important for communicating the participant's experience. After the story was told succinctly, I then identified the key point of the story and sought to remove details that were

not necessary for communicating the general meaning. As Jarrett notes, poetic transcription can be described as, “a powerful and engaging opportunity to recreate complex events through which depth of experience was not lost” (2019: 578).

The ethical consideration this process brought up for me was one that would have come up regardless of how I chose to share the narratives - which was the question of accuracy in relaying the stories told to me. To manage this, I have been careful not to change the meaning of the of the stories, nor to remove details which would reasonably change the reader’s understanding of the participant’s experience. I remained mindful of a potential towards confirmation bias, and a tendency to ‘cherry pick’ only the parts of transcript which were in line with my own life experiences. What was helpful in preventing this, was that I had started analysis without considering that I might reduce the text. I must have known that I wasn’t going to use all of it, but my analysis started without consideration for what parts of the interviews might have lined up with my pre-existing thought. In fact, I was already discovering discourses I had not anticipated. The process of choosing how to condense the transcripts was then about preserving evidence of the discourses I had found rather than shaping them. I attempt to stay close to the participant’s voice doing a microanalysis of terms and word choice, but I also use a technique called ‘empathic imagination’ (Elliott et al., 2018). Used in my work as a therapist, empathic imagination allows me to understand how someone else might have felt in a particular situation to better understand their experience.

TIFDA

In the second half of my analysis chapters, following my micro analysis of the text, I then move towards the macro TIFDA which came up in the transcriptions. Despite its name, Foucault did not create Foucauldian Discourse Analysis, rather this was created by researchers who were interested in the influential role power had on creating acceptable discourses within society, and how discourses changed over time. Ian Parker is a researcher often referenced for creating 20 possible steps for FDA - although FDA should not be prescriptive and can be refined depending on the research project. To help me consider what steps I needed to use, I generalized Parker’s steps into 3 stages, to get to the crux of what FDA sought to look at. These stages were: (1) identifying Subjects and Objects; (2) Identifying how the found discourses reinforce the existing power structure; and (3) The genealogy of the discourses (Langdridge,

2004; Parker, 2010). I then took the questions from the PTMF and integrated them into Parker's method for FDA to create the following TIFDA 'recipe':

1. Step One is to comb through my interviews, or my 'Body of statements' looking for passages where the object (the autism or the autistic traits) are either directly or indirectly referenced. I am seeking to identify excerpts of the interviews in which the Object is in some way present.
2. Step Two is to explore the discourses present in the lyrical transcriptions. Because the autism is not known or accepted in all passages, discourses may be around what it means to be 'normal' or 'different'. In looking at discourses I considered the following:
 - a. How are autistic people or autistic traits categorized?
 - b. Could such traits be linked to trauma responses?
 - c. What is the non-verbal discourse? This might include ignoring or not giving a verbal response to someone.
 - d. What meaning is made by the participants of verbal and non-verbal discourse?
 - e. Is the object problematized? And if so, how?
 - f. Look for contrasting discourses.
 - g. Do the reactions suggest trauma?
3. Step Three is to look at what behaviours the found discourses allow for:
 - a. How is the object regulated?
 - b. How does discourse punish?
 - c. Non-verbal discourse is also an action. 'Positive ignoring' ABA is an example of actioning non-verbal discourse.
 - d. How are contrasting discourses played out? Might allow for hostile behaviours whilst using language that denotes professionalism and calm.
 - e. Throughout, look for the effect of the discourses and the behaviours they permit, as well as how the participant's behaviours express this effect.
 - f. How do "speaking and doing support each other" (Willig, 2013: 132).

4. Step Four is to look at how the participants have accepted or challenged the offered subject positions. Part of the effect on wellbeing is looking at the subject positions offered to the research participants (Willig 2013). My question about wellbeing relies on both the unconscious acting out of the subject role and the conscious acceptance of the subject position so I included explorations of both in this step. I also intertwined these explorations with trauma theory, particularly with regards to 'Assertiveness', 'Adaptation', 'competition' which are some of the survival strategies identified by psychologist, Paul Valant (2007):
 - a. What subject roles does the discourse offer? What kind of people can we be? What can others be?
 - b. Why might some subject positions be more preferable than others?
 - c. How did past (historical) ethnocentric judgments affect the participants internal narrative?
 - d. What practices are available to people in these positions and which ones did they not take up?
 - e. Notice when strong language is used. What does this mean, and does it relate to the feeling of power or lack of?
 - f. What has been the impact of taking these subject positions?
5. Step Five is to look for shared themes between what I analyzed:
 - a. What are the themes?
 - b. What are the untidy bits- themes that aren't shared but seem significant?
 - c. What are the contradictions?
6. Step Six involves 'writing up'. In this thesis, Chapters Six and Seven are more focussed on the discourses professionals were relying on in their roles. In Chapter Eight I focus on the meaning that was made by the participants of their experiences and in Chapter Nine I look at some of the survival strategies employed by the participants. But it is important to note that these are not neatly separated, and there is, from the beginning, an understanding of the impact certain discourses have on the participants.

AREAS FOR FURTHER RESEARCH: THE EXPERIENCE OF THOSE DIAGNOSED EARLIER IN LIFE

All of the participants received their autism diagnosis post-adolescence, meaning that they went through early education receiving messages that they were ‘not trying’ and that any deviances were a product of their choices rather than their cognition. One limitation of this research is that it doesn’t compare how messages are internalized by people who were diagnosed in their childhood. Most of my autistic therapy clients received their diagnosis in their early life and many of them carry a sense of being much younger than their actual age, and in my view, they lack awareness of their ability to do many adult things. In other words, many of my clients seemed to have internalized messages which infantilize them. Other factors which might influence this would likely include where and when they were born and diagnosed. Someone who received a childhood diagnosis of autism in the 1980s in a working-class rural area may have received different treatment from someone who was diagnosed in the 2000s in a metropolitan city. I offer this simply as something the reader might ponder rather than something I can offer strong views on as such a comparison was not within the scope of this study.

SUMMARY

Activist research is grounded in the belief that research *should* be used as a tool for social transformation. This belief aligns with my objective which is to centre the marginalized autistic voice to challenge power dynamics and produce knowledge that can be used to create positive institutional change. In the upcoming chapters I use over 1000 minutes of interview data, created between four research participants as well as my own trauma stories. I recognize that the way I can relay my own story will be different to the way in which I can understand or tell the story of another person. I also bring smaller chunks of my life in throughout my research. I do not seek to approach analysis of my story in the same way I do with my participants’ stories; but I invite the reader to notice parallels or take their own critical evaluation of my experience. I chose to keep the participant numbers low to allow me to spend time delving into the nuances of their stories. I rely on Trauma-informed Foucauldian Discourse Analysis to critically analyze how the deployment of ideological power can unintentionally harm the autistic community.

CHAPTER 3: AUTISM'S BACKSTORY

Deep down in the bowels of the National Institute of Health's (NIH) complex—beneath the research library, and under the labyrinth of clinical trials, and even further down than the top secret laboratories—there exists a sacred room. And in the center of this room, there's only one item—a human brain encapsulated in a clear glass globe, just like the rose from *Beauty and the Beast*. This brain is no ordinary brain. Oh, no. It's the perfect brain, taken from the perfect human, who did all the perfect things. I'll call him John. (Ashburn and Edwards, 2023: 35).

In this chapter I take a critical look at the genealogy of medical discourses on autism. The aim is (1) to gain insight into the role non-autistic researchers have played in shaping society's understanding of what it means to be autistic; (2) to question whether the early 'experts' had the depth of knowledge required to make the claims around autism that has shaped our understanding of it; and (3) to offer a possible foundation for a more modern understanding of autism. But before I talk specifically about autism, I would like to spend a few pages exploring psychiatric 'disorders' as a concept in our society.

THE WOOLINESS OF MENTAL HEALTH LABELS

My main thesis for this chapter is that modern psychiatry is operating on extremely outdated theories about how we understand difference. This may sound like an extreme statement to some, but many people within the field of psychiatry are starting to acknowledge this truth. Boyle and Johnstone note in the Power Threat Meaning Framework (PTMF)

In spite of being so widely used, psychiatric diagnosis has been strongly and persistently criticised on many grounds. These include that psychiatric diagnosis medicalises thoughts, feelings and behaviours that are unusual or differ from the norm; that its categories are not evidence based and do not help us understand the causes of distress; that it sidelines people's life experience, can give them a negative, stigmatised identity... (2018: 32).

Autistic clients I have worked with have used other words to describe how they have been made to feel. These words include: "Broken", "Wrong", "Less-than." Because of the effect such

medical diagnoses of difference can have on a person it is worth looking at how we have come to decide what constitutes 'normal' today. The concept of mental 'disorders' is a product of the ecology in which it grows, becoming 'disorders' only in certain environments. In *Madness and Civilisation*, Foucault (1988) asserts that 'madness' is dependent on the current social expectations at a given time: what we view as 'normal' is simply a representation of that which is typical behaviour in the moment - meaning what is abnormal, or 'disordered' is not set in stone - it can and does change. A somewhat recent example of this is the shift of discourses around homosexuality which - as late as the 1980s - was still listed as a mental disorder in medical handbooks. Imagine for a moment a society which regarded the LGBTQIA community as irrational and disabled simply by virtue of their sexual preference. And - if we did think that - it would be a self-protecting discourse which any professional or parent could use as a justification for forcing treatments. Gender dysphoria is still listed as a disorder.

WHY WAS CATEGORIZING ABNORMAL IMPORTANT IN THE FIRST PLACE?

Foucault believed that the origins of psychiatry were born out of a societal desire to contain those who could not neatly slot into the workhouse culture required for the industrial revolution, the world wars and then also, compulsory education. Persons who weren't viewed as contributing members to society were categorized and institutionalized. He termed this the 'great confinement' (Foucault, 1996).

To further illustrate this point, we can look at what is often referred to as the psychiatrist's Bible, The *Diagnostic and Statistical Manual of Mental Disorders* (DSM, 2013) which is a work listing, categorizing and defining mental disorders. Many readers may have already heard of the DSM, but some may be surprised to learn the initial reason for developing this system of classification for mental disorders was simply to determine who was 'fit to work'.

In the 1840's the United States of America created a census where citizens who were deemed unfit for work were recorded as having 'idiocy/insanity'. Many racial minorities were automatically ticked in this category (Wright, 1896). Whilst this may seem shocking, it's my guess that the census takers did not feel as if they were acting in a discriminatory way. At the time, many social scientists believed people of colour were more likely to be members of this category due to their genetic makeup. There was a belief that they were our 'vulnerable' members of society and denying their right to participate fully in life was an act of safeguarding

both them and society. It's important to recognize the ignorance rather than intentionality behind such acts because discriminatory acts today are often committed by people who truly believe they are making benevolent decisions out of a sense of morality. For many, including myself, this is even more infuriating. But when we story past acts of discrimination as clearly 'malicious' or 'ugly' - we disguise the true nature of discrimination, making it harder to recognize it in the now. As Craft points out:

Discrimination isn't always obvious. Sometimes discrimination is cloaked in good deeds and good intentions. Candy-coated with awards and recognition. Sometimes discrimination is a result of purposeful initiatives. A means of branding. (2020: 55)

The census then went through many revisions until in the 1950's the first volume of the DSM was published.

Once every child was required to be in school, psychologists and psychiatrists began to discuss what to do with children who struggled to slot into the assembly line that makes up the school system. To save children from being institutionalized, psychologist Alfred Binet developed the first intelligence test in 1905. Binet's test was meant to keep children from being excluded from school, but at the same time it marked the start of profiling normalcy in children. Similar to the aim of establishing who could be productive in the workforce, children's psychology hinged on much the same points. Johnstone and Boyle point out, 'that diagnostic criteria such as "often arguing with authority figures" or "having poor time management" or "making careless mistakes in schoolwork or at work" (2018: 45) would all be traits which cause difficulty for institutions. In this way school could be seen not just as a tool to educate but also as a setting to test the child's ability to conform to the demands of the institution. Pathologizing discourses are used to turn things that challenge the smooth functioning of institutions into faults with the person. An example offered by one of my clients was the phrase 'school resistant' which immediately frames issues as a problem belonging to the child, rather than the school. Social media influencer, NeuroWild (2023), created the illustration on their Facebook page to highlight how discourses can direct our attention away from the important issues.

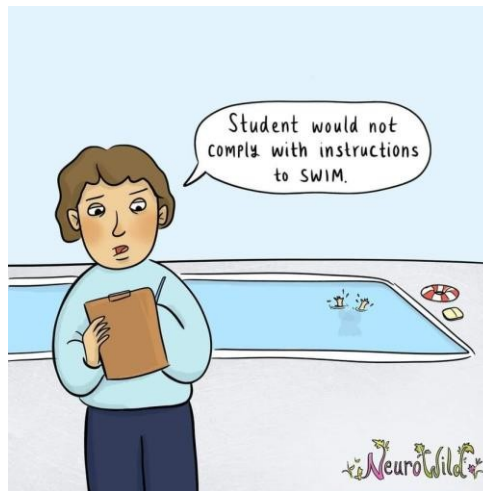


Figure 2 'Student Didn't Comply.'

And - like always - these terms are used to Other, to separate that which is acceptable from that which is not: but that which is acceptable, continues to be based on the cultural norms at the time and that often has something to do with material gain for those in power.

Whilst clinical categorizing may have been used as a blunt instrument to decide who was fit to work, I believe other tools were used to fine tune conformity within the population at large. When considering what was happening in the mid-1900s, it occurred to me that the new invention of the television set - the world's first visual mirror of what normal is supposed to look like - may have held an ideological power influencing ideas about how we were meant to look and behave and what it meant of our character if we deviated from the accepted norms. To this end, racial minority groups were often criminalized in films and TV. Between capitalism and media there was a refinement of what exactly 'normal' was supposed to look like - along with who we could see as 'good' and 'bad'. Foucault's major works all looked at 'normal' versus 'abnormal'. Ultimately 'abnormal' was always *in contrast* to 'normal' and the more rigidly defined 'normal' became the more ways in which one could be 'abnormal.' In the 70 years since the first edition, the DSM has tripled in size. As Boyle and Johnstone (2018) note, sociologist Bruce Cohen has shown that each edition of the DSM adds more criteria about what counts as unacceptable or 'abnormal' behaviour in schools and workplaces.

Today, according to the World Health Organisation (WHO, 2019), the term 'mental disorder' is any disorder that is understood to be "a clinically significant disturbance in an individual's cognition, emotional regulation, or behaviour". People often use terms like 'mood disorder',

or 'personality disorder' or 'cognitive disorder' to represent a perceived difference between different types of mental disorders. But – if - when - you stop and consider the words - Mood, Personality, Behaviour, Cognition - these words all have to do with the mind, how we experience the world and how we outwardly express our experience. It is my understanding that all mental 'disorders' *are* cognitive because you cannot separate behaviour, personality, or mood from someone's cognition. If you consider this for yourself and find that you agree, then keep this point in mind as you read because this affects how we might change our understanding of autism.

PATHOLOGIZING ABNORMAL: MENTAL 'ILLNESS' IS (NOT) 'AN ILLNESS LIKE ANY OTHER.'

People have medicalized psychiatric labels as a way of suggesting that they are scientifically measurable the way other physical conditions are. But the reality is that they are not. To explain this, I have – as previously noted - drawn quite heavily from the Power Threat Meaning Framework which has covered this topic thoroughly. Johnstone and Boyle (2018) state that the diagnosis process will likely start in the same way any other medical diagnosis starts: The patient goes to see the doctor and describes a set of symptoms they are experiencing. This process is subjective both for the patient and the doctor. The patient is trying to explain what they understand to be outside the realm of normal, whether that is abnormal fatigue, or pain, or dizziness. The doctor is making assumptions about the patient's meaning and ability to gauge their symptoms. She is then listening for clusters that might fit together so she can make a first guess at the underlying problem. Following that, she will test her hypothesis by taking a blood or urine sample or sending the patient for an X-ray. But when it comes to psychiatric labels there is no objective test. The process stops at the subjective hypothesis. Johnstone and Boyle (2018) discuss this process in more depth concluding that in the absence of biological markers, the DSM's categorization system is determined through a voting process to establish distinctions between 'normal' and 'disordered' conditions. These designations, referred to as 'medical labels,' essentially represent subjective viewpoints. According to Davies (2013), the decision-making process within these committees lacked scientific rigor, resembling more a group of friends deciding where to go for dinner.

Mental health is not tested in a biological way, and differences in the brain are only just starting to be tested. But more importantly, neither mental health nor cognitive differences are

diagnosed using physical tests. All psychiatric diagnoses are based on the opinion of the clinician. As Boyle and Johnstone note:

Relying on subjective judgments like these means relying on social norms. Deciding whether someone is having 'unusual perceptual experiences' or 'excessive guilt', or whether they are 'often touchy and easily annoyed' or have 'inflated self-esteem' or even 'deficient erotic thoughts or fantasies' depends on judgments about how we should think, feel or behave in certain circumstances. Diagnostic criteria also often say that the person's so-called symptoms should cause them distress or interfere with day-to-day functioning. But how we feel about our own emotions and behaviour also depends on social norms and expectations about how we should feel and behave, what we should and shouldn't be able to cope with and what our reactions to events might mean (2018: 43-44).

SOCIAL MODELS OF DISABILITY

Whilst "the medical model of disability relies heavily on a colonial-capitalist worldview that values conformity, and those that fall outside the norm are inferior" (Ashburn & Edwards, 2023: 41), The World Health Organization claims that disability is "not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person's body and features of the society in which he or she lives" (WHO, 2019). This definition recognises disability as a societal construct and not something which solely belongs to the individual. With this understanding, that which we currently view as a disability today may not be viewed that way in the future.

In theory, we could wholly reject the notion of any sort of disability if we put the disabling element entirely on a society that does not accommodate the individual. A seemingly more diplomatic discourse around disability is to suggest some individuals are simply more *vulnerable* to distress but "vulnerabilities and stresses are also still seen as an 'illness', in much the same way as infections that result from a weak immune system" (Leeming, 2009: 15).

So, do people with 'mental disorders' have a metaphorically weakened immune system? I consider that when European explorers arrived in the Americas in the late 15th and early 16th

centuries, they brought with them diseases - such as smallpox, measles, influenza, and typhus – and these spread rapidly among the indigenous populations who had no natural immunity to them. The native peoples of the Americas had not been exposed to these diseases before, so they had no built-in immunity. As a result, the diseases caused devastating epidemics. Most autistic people I know struggle to tolerate capitalist demands such as 40+ hour work weeks, crowded spaces, open-plan offices, changes with short notice or arbitrary hierarchies. In my view, the vulnerability stress theory still tends to alleviate society of a need to change while creating an understood message that *some* people are more susceptible to distress. As Boyle and Johnstone note “by locating the ‘real’ problem with those who suffer. Both the biopsychosocial and vulnerability-stress models can discourage us from looking too closely at what has happened, what it meant to the person, and how these ‘stresses’ came to be part of their life” (2018: 69).

Regardless of the language we use, there is always going to be a majority of people who work a certain way and individuals who have divergent ways of being, whether it is physical, mental, spiritual, sexual or something else. There will always be clusters of people that make up minority groups. However, we are more conscious of human rights when it comes to *some* minority groups than others. Some differences are considered more taboo than others. I argue that autism is a culture that is partially disabled because it is in the minority, but also partially because people see it as unacceptable to be different in this way.

I particularly dislike the word ‘vulnerable’ often used to describe a ‘disabled’ person. I agree that we are vulnerable, like all people are. Soldiers in combat are vulnerable. Minority groups are vulnerable. People who don’t easily slot into capitalistic demands are vulnerable. And we are breaking under the pressure. When a human is living under constant stress which exceeds their ability to cope, they are vulnerable. All human beings are vulnerable. That is what it means to be human and alive. Below I explore the clinical history of what is currently called ‘autism.’

FROM ‘DEMENTIA PRAECOX’ TO ‘SCHIZOPHRENIA’ TO ‘AUTISM’

In my view this section is instrumental to answering the question many have: Is autism on the rise?

In his book *Unstrange Minds: Remapping the World of Autism*, Grinker (2007) - who is both an anthropologist and a parent of a child with autism - contends that evolving definitions of cultural phenomena have had a significant impact on the approach of the medical community and the public's perception of mental health. Grinker not only highlights the growing awareness of autism in society, but also identifies key factors responsible for its increased prevalence, including: (a) the broadened diagnostic criteria; (b) the change in psychological labels; (c) increasing demand in schools; (d) increased awareness by members of the public accompanied by reduced stigma of difference; and (e) accompanied by greater support.

I agree that we have relabelled other conditions with the term 'autism'. That will make it seem like the numbers are growing, when in fact what we are now calling 'autism' has always been there. I think we relabel for two reasons: (1) We are seeking to give new names to terms that have stigma attached to them; and (2) We like to feel like we have developed a new concept, and - because of the subjective way in which inner experience is discussed - we can often argue that this thing - over here - is very different to that thing - over there - and it deserves a different name. Of course, sometimes this is true. But also, sometimes it is not. We just like naming things.

To argue this point I look at the term 'dementia'. Historically the term dementia did not mean what we think of it as today: predominantly a term we understand to mean memory loss in the older population. Dementia was originally described as a psychosocial 'incompetence'. In other words, it was used to describe people who were deemed to be bad at socializing. The term dementia has been around since 50 BC and has been used in this very general way to understand people who were noticeably different in their way of socializing. Although the ethnocentric judgment isn't that they were different in how they socialized, but rather that they were *bad* at socializing.

In the 1800s the term *praecox* (pronounced: prey cox) was added to create 'dementia praecox', which was a way of expressing the idea that such dysfunction could be seen in people of all ages. In 1908 the term 'schizophrenia' was introduced by psychiatrist Eugene Bleuler to replace 'dementia praecox'. Like dementia praecox, we need to understand that the term 'schizophrenia' was *also* not what we think of it as today. When Bleuler first introduced the term, schizophrenia was a diagnosis given to people who seemed to have a loss of contact with

reality, frequently through indulgence in fantasies. Bleuler used the term 'autism' to describe this way of being. At first, 'autism' was used only as a description rather than as the name of the disorder itself. Over time schizophrenia evolved to include traits of hostility, aggression and paranoia. In *The Protest Psychosis: How schizophrenia became a black disease*, psychiatrist Jonathan Metzl (2009) points out that this label was increasingly given to racial minorities expressing hostility due to treatments of marginalization. Not unlike how hysteria was applied to women suffering from abuse (Herman, 1994). I think of Binette's attempts to save school children from institutionalisation. It's not difficult to imagine that benevolent clinicians might *not* have wanted to give this term to young white children with similar presentations. So, the point was made that young white children who go into their own world (and also often exhibit aggression when overwhelmed) are very different to adult black men who do the same.

The term dementia praecox was gradually replaced by the term schizophrenia - which initially had a meaning that included what is today considered the autism spectrum. Dementia praecox, schizophrenia and autism have all seemed to hinge on the assessment that the holder of such labels have an inferior or atypical way of socializing. If we accept that these are different terms for the same thing, then we can look at over 200 years of clinical recordings on autism as opposed to just 70 years. I can imagine that my suggestion to do this might upset many people owing to today's stigma attached to schizophrenia. I believe that the way schizophrenia is understood today by the general public is *highly* discriminatory and unjust. We should not distance ourselves from this term because of the stigma it holds.

It's worth noting that in the UK schizophrenia is categorized as a 'mental illness' and autism a 'cognitive condition'. In the UK people with 'mental illnesses' are able to be sectioned or hospitalized against their will, while people with 'cognitive conditions' should not be. When considering the arbitrary differences between 'mental illness' and 'cognitive conditions' this seems unfair: what it comes down to in our current discourse is about what is dangerous. This is not a new prejudice. In the 1950s people could be arrested or hospitalised for being gay. The prejudice is the same - the object is different. Throughout the history of humans, we have had divergent styles of socialisation. Terms which have been used to describe this have been clinical and non-clinical such as: 'Touched,' 'Weird,' 'Eccentric,' 'Schizophrenic,' 'Autistic,' and so on. We should look past the labels to see what they are describing and consider if they are describing the same thing.

THE GENEALOGY OF CLINICAL DISCOURSES ON AUTISM

In 1925 Russian child psychiatrist, Grunya Sukhareva started to identify traits that were very similar, if not the same as Bleuler's schizophrenia. Sukhareva described the children she studied as having a 'flattened affective life', 'lack of facial expressiveness and expressive movements, 'keeping apart from their peers', 'talking in stereotypic ways' with 'strong interests pursued exclusively'. This description is strikingly close to how we understand autism today. Sukhareva published her findings in a medical journal detailing out the traits of six children in her clinic in Moscow who presented as *withdrawn and highly focused on their own interest* (Posar and Visconti, 2017). Shortly after Sukhareva's works were translated into German, physician Georg Frankl and psychologist Anni Weiss recorded similar traits seen in the children they worked with in Vienna, such as what they considered to be a 'disconnect between facial expressions, body, language and speech' and 'fixations or communication impairments' (Posar and Visconti, 2017).

In 1932, seven years into Frankl and Weiss' research, they were joined at the clinic by a junior paediatrician, Hans Asperger, then aged 25. Asperger, who Asperger's Syndrome is named after, has been regarded as one of the two founding fathers of autism. Asperger wrote several papers on what he referred to as 'autistic psychopathy'. His papers were finally compiled and published as a postdoctoral thesis with Vienna University in 1944. Frankl and Weiss were Jewish doctors and, likely due to the antisemitic climate at the time, were not credited in Asperger's publications. Frankl, Weiss and Asperger worked together for more than eight years before Weiss and Frankl left Austria in 1941 to take solace in America with the help of Jewish psychologist Leo Kanner, where the three of them worked at John Hopkins University in Baltimore Maryland.

In 1943 Leo Kanner published the foundational paper 'Disturbance of Affective Contact' in the medical journal *Nervous Child*. By this time schizophrenia had taken on a new life and stigma. With all other papers on Asperger's Syndrome existing in Russian and German, the continents were separated by a World War. Thus Leo Kanner's publications about autism were long regarded by many as the *first* on autism (Baker-Rogers, 2013; Nadesan, 2015). Kanner's account of autism became the account that would shape clinical discussions on autism for the next 40 years.

It was not until 1981 that researcher Lorna Wing broke new ground by publishing a paper in *Psychological Medicine* which alerted the English-speaking world to Asperger's works. In 1991 developmental psychologist Uta Frith translated Asperger's publications into English. It was with this translation that what had once just been called Autism became referred to as the Autistic *Spectrum* Disorder- later updated to Autistic Spectrum Condition in many circles. Not only was there an increase in people being diagnosed, but also, because more members of the public were being diagnosed or knew someone with a diagnosis, more members of the general population were hearing the terms Autism and Asperger's Syndrome.

Today, The DSM-5 offers the following diagnostic criteria to describe autism.

To meet diagnostic criteria for ASD ... a child must have persistent deficits ...A.1 - A.3, plus at least two [from] B.1. -B.4.

A. Persistent deficits in social communication and social interaction across multiple contexts:

- a. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
- b. Deficits in nonverbal communicative behaviours (who decides what this should look like?) used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication. (Again, how can we know what is being communicated?)
- c. Deficits in developing, maintaining, and understanding relationships, (Why is the onus on the autistic minority to understand the non-autistic majority?) ranging, for example, from difficulties adjusting behaviour to suit various social contexts; to

difficulties in sharing imaginative play or in making friends; to absence of interest in peers. (This is based on an assumption that an interest in peers is the ideal. To challenge this one might consider if being a-sexual should be seen as a disorder.) (DSM, 2013: 50-51).

In the above I have underlined the words that link to social norms and challenged some phrasing (in bold and brackets) that presumes what it means to be normal. Clinicians are literally being openly instructed to diagnose people based on how much they fail to conform to social norms. Below I continue to underline wording that is based on a presumption of that which is normal.

- B. Restricted, repetitive patterns of behaviour, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
 - a. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
 - b. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behaviour (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
 - c. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 - d. Hyper- or hypo reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement) (DSM, 2013: 135).

In Section B diagnostic criteria is based on atypical presentations in two of the following four areas: (1) a need for sameness; (2) a seeking of repetitive stimulation; (3) an intensity in one's interest; and (4) responses to sensory stimulation.

Although Section B doesn't overtly state that this is about social norms, it simply seems to presume an understanding of what is 'rigid thinking patterns', 'highly restricted interest' and 'hyper or hypo reactions to sensory experiences'. Again, I have underlined some of the words that indicate a diagnosis will be based on social norms.

For example, a 'need for sameness' can be commonly seen in a person's need for a particular morning routine. Many people will say they are quiet for the first hour or so in the morning, or 'need' their coffee before they're ready to engage with the world. Others might have an evening ritual to unwind from work. I would argue that whilst not everyone has a 'need for sameness' many people do and its clinical significance is based on that which is viewed as a normal need for sameness or an abnormal need for sameness.

In the second category they look at 'seeking of repetitive stimulation'. Examples of this might include: popping bubble gum, petting a dog, tapping a foot to music, doodling when stressed, flapping one's arms when anxious, smoking, listening to a favourite song repeatedly, masturbating in private or masturbating in public. Again, some are socially acceptable others not.

In the third category they are looking at an intensity in one's interest. For example a football fan who never misses a game, a groupie who has their favourite band plastered all over their wall, a train spotter, a person who explains life through Star Wars metaphors, a person who can recite America's declaration of independence by memory, or a PhD student.

The last category is literally asking the clinician to judge whether the patient over or under reacts to sensory stimulation. I think of the conflicts I have with my husband about whether the house is too hot or cold. His music is *never* too loud (even though it shakes the house), but mine often is. He laughs like a little girl if I touch him too gently. No one in my family likes crowds. For my son, three people is a crowd. I used to feel that way when I was younger, but now a grocery store on a Saturday is a crowd. Some people love crowded noisy night clubs.

What is normal? And at what point do we decide that our judgment of this means someone else is disordered?

After typing up the diagnostic criteria for autism I wondered how this would compare to the diagnostic criteria for schizophrenia. What I found was that whilst the language was different the criteria was quite similar: both diagnoses hinged on perceived difficulties for social communication and atypical motor movement. After reading the description on schizophrenia I came to a sentence which read,

If there is a history of autism spectrum disorder or communication disorder the diagnosis of schizophrenia is only made if prominent delusions or hallucinations are present along with other symptoms for at least one month (DSM, 2013: 136).

What I understand this to mean is that the clinicians who have contributed to writing this criterion do recognize the very close similarities listed for these conditions, save the fact that 'delusions' or 'hallucinations' are listed as a feature for schizophrenia and not for autism.

I would argue that many people with autism have such rich fantasy lives they could be described as having 'delusions'. Or they have hallucinations which may not be visual but could be auditory or draw on any of the senses. Autistic people are known for their hyper sensitivities. Being able to remember something so extremely that we can reexperience it in our body is not unusual. What makes such sensory remembering a hallucination is if the person loses touch with reality to the extent that they cannot tell what is real. What is often not acknowledged when considering this as a feature of poor mental health is that humans often have conflicting views on what is real. I know many people who have a strong faith in God and others who don't believe in God at all. But because such a large percentage of the population holds a religious faith, we do not classify that as a disorder. There seems to be a non-formal agreement to simply respect the right of people to believe in something they cannot see. To that end, what is delusional thinking?

Just now I had a bitter thought about being treated like I'm delusional when I've spoken out about experiences of discrimination. Then I thought, that's not really relevant - but actually it is. This was the point Metzl (2009) was making when he said that many black men were diagnosed with schizophrenia. Their anger and sense of injustice over how they were treated

was seen as 'delusional'. Women who suffered emotional distress were labelled 'hysterical' for the same reason. Middle class, white male, god-fearing physicians, couldn't understand why oppressed groups would feel such a sense of injustice or anxiety. We must be delusional.

The DSM then goes on to state, "Symptoms ... may not become fully manifest until social demands exceed limited capacities" (2013:136) thus making the point that autism may not be disabling until we are in an environment that pushes us too far! In other words, to me this strongly suggests that the presentations being diagnosed are actually stress responses rather than core traits of autism. Another way of understanding this is that people may not get the understanding they need until they are already suffering from lack of it.

SOCIETAL DEMANDS

The idea that societal demands affect how much of our autism is seen by others could also offer another explanation as to why there has been a massive increase in autism diagnoses since the 1980s. Boyle and Johnstone (2018) make the observation that the 1980s saw the rise of neoliberalism as a dominant ideology in many countries, particularly in the United States and the United Kingdom. This was largely due to the influence of figures such as Ronald Reagan and Margaret Thatcher who implemented policies that reflected neoliberal principles. Implemented tax cuts, deregulated industries, and spending cuts on social welfare programs led to a period of economic growth, but also increased inequality. Institutions became more demanding of conformity with less and less social support and less attention to the wellbeing and needs of individuals. Such behaviour is permitted through discourses that encourage independence and chastise attention to personal needs as 'weakness', 'laziness' or 'dishonesty'. One way of avoiding such punishing discourses is to be diagnosed with a clinical difference. This more rigid demand for 'order' means there are more ways than ever before for us to be '*disordered*'.

Boyle and Johnstone (2018) make the point that our capitalistic society promotes the myth of personal independence by suggesting that those who can function in society as it is laid out are more independent than those who struggle. Another way to consider this is that society is set up to help people at every turn and we don't highlight this constant support (e.g., road and shop signage, police officers, coffee shops, sales assistants, doctors, nurses, teachers, maps

etc...). People make use of auxiliary aids constantly throughout the day without acknowledgment. Only when someone requires something outside the typical, such as braille writing on a sign, or slower speech, or explicit speech, do we start to suggest they are not as independent as the rest of us. But independence is a myth.

THEORY OF MIND

Early discourses came from non-autistic researchers who lacked the necessary understanding of what it means to be both neurotypical *and* autistic. The expert who sits outside the group they are studying cannot consider the inner experience of those they are Objectifying and what they end up describing is simply their observations about the Other. Foucault's genealogical method of analyzing discourses allows us to examine how things could have been different, acknowledging that discourses are influenced by the political and societal climates of their times. We need to consider how the descriptions of 'what autism is' might be reframed were the description to be given by an autistic person explaining their way of being in the world.

A 'social communication deficit' (DSM, 2013) is said to be a primary trait of autism as it was with dementia praecox and schizophrenia. Whilst communication can mean many things, such as the ability to speak at all, the DSM clearly refers to *social* communication suggesting that this is not about the ability to speak but about the ability to socialize which can only be evaluated according to cultural norms, as indicated in other parts of the DSM's description of autism. Close to the idea of a 'social communication deficit' is a concept called 'theory of mind' (Frith, 2005) which is one person's ability to understand what someone else is thinking or feeling. The DSM (2013) refers to the potential autistic person as failing to 'understand relationships'.

In 1985, Baron-Cohen, Leslie and Frith co-authored the article "Does the autistic child have a 'theory of mind'?" . Although the article itself might not be well known amongst the general population, its theory that autistic children were unempathetic gained plenty of attention from professionals and this has become one of the core stereotypes surrounding autism. Baron-Cohen has since withdrawn these findings but as Boyle and Johnstone (2018) point out, retraction to academic findings gets a lot less attention. Theory of mind is not mentioned In

the current edition of the DSM, but this concept is still taught to professionals around the world (Ashburn and Edwards 2023; Gernsbacher and Yergeau 2019).

When making the declaration that autistic people lack ‘theory of mind’, Baron-Cohen, Leslie and Frith (1985) did not question if autistic people can understand other autistic people, or if non-autistics can understand autistics. The only question considered was whether autistics could understand non-autistics. The foundation of the research rests on an assumption that the non-autistic person makes correct judgments of the other. Following this ethnocentric assumption, the researcher can make a series of tests to see if the person they are observing performs as the researcher expects.

An initial literature search revealed a few papers which look at differences in ‘understanding’ between autistics and non-autistics. Perhaps the most notable is the peer-reviewed article published in the *Society & Disability* journal, “On the Ontological Status of Autism: The ‘Double Empathy Problem’”, written by Damian Milton, an autistic researcher and father to a son with autism. Milton (2012) argues that traditional theories of empathy, which focus on an individual's ability to understand and feel the emotions of others, are insufficient for understanding the social experiences of autistic individuals. Instead, Milton proposes a model of ‘double empathy’ which recognizes that empathy is a two-way street and the ability to understand and connect with others is influenced by the social and cultural context in which interactions take place. Milton draws on both theoretical and empirical evidence to support the model and highlights the importance of recognizing the perspectives and experiences of autistic individuals in understanding their social interactions.

According to the theory of the ‘double empathy problem’, communication difficulties are not due to autistic cognition alone, nor do they belong solely to the autistic person. Instead, difficulties are caused by a breakdown in reciprocity and mutual understanding that can happen between people with differing ways of experiencing the world. Many misconceptions occur because there is an assumption that there is a “shared understanding of signals and meanings” (Sinclair, 1993: 97). The ‘double empathy problem’ points out that there is not one correct perception and that neurotypicals will also have difficulty correctly reading the subtext of the autistic sociality. Milton’s (2012) paper has been widely acknowledged for calling into question an assumption, which has dominated clinical research and is widespread in the

general population, that there is a single correct way of socializing and autistics have a deficit in this area. This idea is represented in three further empirical studies (Brett, 2019; Morrison, 2019; Sheppard, 2016) which illustrate the double empathy problem using experiments.

Elizabeth Sheppard, assistant professor at the University of Nottingham, led a study called, “How easy is it to read the minds of people with autism spectrum disorder?” This study involved showing the research participants, all neurotypical adults, videos of both neurotypical and autistic people having reactions to events. The findings indicated that the participants more accurately described the reactions of the neurotypicals in the video than the autistic persons in the video. They concluded that “because neurotypicals are ineffective in interpreting the behaviour of those with ASD, this could contribute to the social difficulties in ASD” (Sheppard et al, 2016: 142).

Heasman & Gillespie (2019) from the London School of Economics interviewed 22 autistic people and non-autistic family members about a conflict they had. The findings showed that the autistic person could often explain not only their perception but also the perception of the non-autistic person. However, the non-autistic person was often only able to explain their perspective and frequently misunderstood the perspective of the autistic person, attributing this misunderstanding to the fact that the other had autism. The study also found that autistic individuals often rely on explicit communication, rather than relying on nonverbal cues or social norms. This can involve asking direct questions or giving explicit explanations, which can be helpful in avoiding misunderstandings. Unfortunately for autistic people, many non-autistic people discount their own mind blindness or intolerance around different ways of thinking and interacting. The autistic person is then held solely accountable for miscommunications, differences in socializing or being in the world (Baker-Rogers 2017; Milton 2011a; Moat 2013; Tajfel and Turner 1979). This is currently not regarded as discrimination in the same way that bias surrounding race, sexuality, religion or gender might be.

Kerriane Morrison (2019) conducted her PhD research, *Outcomes of Real-world Social Interaction for Autistic Adults Paired with Autistic Compared to Typically Developing Partners*, at the University of Texas. The study consisted of 79 autistic adults and 49 non-autistic adults at a ‘getting-to-know-you’ function, where the participants mingled and held brief one-on-one conversations with each other. Following the conversations, the participants rated how they

felt about the people with whom they had spoken. The outcome was that autistic participants felt they connected better with other autistic participants, whereas non-autistics felt more warmth towards other non-autistics. Dr Sasson commented, “If autistic people were inherently poor at social interaction, you’d expect an interaction between two autistic people to be even more of a struggle than between an autistic and non-autistic person. But that’s not what we found” (Fontenot, 2020: 24). Instead, the study found that autistic individuals have a unique way of creating shared understanding with others, which the author refers to as ‘neurodivergent intersubjectivity’(Morrison, 2019). This involves a focus on shared experiences rather than shared emotions or mental states.

CROSS NEURO-TYPE COMUNICATION PROBLEMS

Blogger and author Karla McLaren writes from a neurotypical perspective about her experiences working in an educational setting with autistic students. While I promote the autistic voice, I use McLaren’s blog because she writes about some misjudgments she and other neurotypical professional helpers she works with hold about autistic students. McLaren described her initial anxiety of beginning work with autistics, wondering if she would be qualified to work with people assigned with this label:

I knew from my early reading that autistic people were allegedly mind-blind... In my first few days with my new friends, I looked everywhere for this mind-blindness and this lack of empathy — but I didn’t find either one. I didn’t see any lack of sensitivity; in fact, I saw hypersensitivity — painful hypersensitivity. And I didn’t see mind-blindness either; instead, I saw a continual, time-lagged confusion about what was going on with and between neurotypicals. I understand this confusion very well, because with my overabundance of empathy, I often find neurotypicals frustrating and emotionally incomprehensible. Here’s why:

The following are normal everyday behaviors among neurotypicals: lying about their feelings; avoiding sensitive subjects that are glaringly obvious; leaving important words unsaid; pretending to like things they don’t like; pretending they’re not feeling an emotion that they’re clearly feeling; using language to hide, obscure, and skirt crucial issues; attacking people who

frighten them without ever realizing they're full of fear; stopping all forward progress on a project without ever realizing they're full of anger and grief; and claiming that they are being rational when huge steamy clouds of emotion are pouring out of them. Neurotypicals are often emotionally exhausting (2011, Empaths on the Autism Spectrum, part 1).

While some autistic people may respond to a challenging environment by repressing their self-expression, others learn to express themselves in extreme ways. In her article "The Double Empathy Problem in Care", professor Rita Jordan (2019) writes that mental health staff 'including psychologists' often fail to understand the autistic perspective and a lack of understanding of the behaviours of the autistic person can leave staff applying a neuro-typical meaning to behaviours which seem challenging. This can lead to staff, who lack such understanding, to become abusive in order to regain control. When one person has a 'label' setting them apart from the dominant culture, that label is often used to absolve the non-labelled person of responsibility (Milton 2012; Said, 1978). This happens because it is assumed there should be an understood shared sense of reality, and that the autistic person has an 'inability' to understand that single reality.

UNPROCESSED KNOWING

'Central Coherence' is a term coined by Uta Frith to describe a filtering of information:

In the normal cognitive system there is a built-in propensity to form coherence over as wide a range of stimuli as possible, and to generalize over as wide a range of contexts as possible. It is this drive that results in grand systems of thought, and ultimately in the world's great religions. It is this capacity of coherence that is diminished in autistic children (1989: 100).

Frith considers a 'strong' central coherence as the ideal and deviations away from that as a deficit. But autistic researcher Erin Manning proposes an alternative view. Using the late American psychiatrist Daniel Stern's (1985) theory on infant development, Manning asserts that autistic people continue to linger near the core self stage, where the infant has developed the skill of organizing its experiences but does not yet separate their sense of self from their experience. The sense of self is in the relationship "human-to-human or human-to-object" (Manning, 2018: 2). Another way of understanding this is to say that autistic people tend towards more *symbiosis* with their environment. A person who is fully immersed in their

experience will be more disinhibited. This full immersion or symbiosis with one's experience can lead to (1) extreme empathy; (2) sensory sensitivity along with an intense response- when things in our environment are changed without our consent it can feel like *we* are violated; and (3) understanding a situation on a somatic level before an analytical one and thus struggling to articulate their experiences to others. This is in line with research conducted by Henry and Kamila Markram (2017) who proposed the *Intense World Theory*, which suggests that the autistic brain is hyper functioning and thus the autistic person experiences the world as a bombardment of stimuli. This bombardment then leads to a 'weak central coherence' (Frith, 1991) in which an autistic person is not filtering out information in the same way a non-autistic person might.

I would say that this idea of unprocessed knowing is actually in-line with the etymology of the word 'autism' (autos) which means self or same and describes a state of being in an inseparable awareness of oneself from one's environment. An example of this might be found in an anecdote from a client who explained part of their experience as an autistic person is that they don't automatically privilege information the way others might expect stating: "People are interesting but so are other things. The physical environment in the room might be just as interesting or distracting as the people". Of interest are several works which refer to or explore the topic of extra sensory perception amongst the autistic community.

Frith (1991) makes the point that a weak central coherence would lead to an autistic person struggling to make sense of religion. Reframing this concept, William Silverman (2006) wrote *Autism and the God Connection*, which is an exploration of how autistic people have experienced a knowing, often of future events, or seemed connected with late family members. This makes me think of Plato's cave allegory in which people are chained to a cave wall only able to see the shadows being cast upon the wall from the sun. The sun represents the truth and the shadows represent the stories we tell to make sense of the truth. Whilst those looking at the wall may have grand stories, only some were able to leave their chains and see the truth. Perhaps they could not conceive of complex stories, but they could connect with something unprocessed and instead just 'know'.

I am personally interested in this because I would say I have experienced such things throughout my life. I remember practicing the alphabet with a grandmother who had passed

the day before my 1st birthday. I have had precognitive dreams. I had a phone call with a late grandfather when I was standing in the room where he had passed eight years earlier. In most situations I was told my spiritual experiences were my imagination and my precognitions were coincidences. It wasn't until reaching my forties that I started to more firmly belief in my perception realizing that many people simply didn't have these experiences and were only making meaning through their own understanding of the world. It is another ethnocentric judgment about something that might simply be an invalidated gift of autism for some of us. I should clarify that I know autistic people who don't have such experiences. I wonder what else unprocessed knowing might influence and could this explain the overlap between neurodiversity and LGBTQ community. But I start to venture outside the scope of this research.

Both Manning (2020) and Frith (1991) make the same observation, but Frith (1991) frames this as a deficit without room for considering how it might also be a gift neurotypicals tend to lack. In a moment I will look at how symbiosis can be a gift, but first I would like to explore how psychologists came to decide what was developmentally appropriate. It wasn't because there is a right or wrong way to develop, but rather that there seemed to be typical developmental stages that the majority of people would reach at different times in their lives. These are called 'Life Stages' and charts have been created by many psychologists over the years such as Freud, Piaget, and Erikson, etc. to illustrate these stages. But then the charts, rather than being seen as a reflection of the norm, became regarded as a benchmark for what is normal / healthy / appropriate.

If we could let go of the idea that working counter to the norm is automatically a deficit, we could instead recognize the gifts that both ways of working offer. While strong fielding has the benefit of progressing through a busy and ever-changing environment (a capitalist environment) at a quick pace, an unfiltered perception can lead to an awareness of one's environment which is often missed. Below I have created a table to compare a deficit-based and strength-based framework of central coherence:

Table 1. Refiguring Central Coherence	
A WEAK CENTRAL COHERENCE	A STRONG UNPROCESSED KNOWING
A decreased ability to organize information.	An aptitude for unfiltered perception. Sensing much more than is typical.
A hypersensitivity to one's environment which leads to fragility. Particularly in the wrong environments. Struggles with working in crowded places. I struggled working in busy school environments.	A fine appreciation for sensory stimuli which leads to creativity. Especially in the right conditions. Great with detailed work. I worked much better as a 1:1 therapist.
A shutting down or lack of engagement with the world around us.	Taking time to process the unprocessed. A tendency towards introspection, creativity, and philosophical thought.
Trouble with timekeeping and structure.	Absolute engrossment with a project or task.
Not prioritizing that which others find important.	A tendency towards challenging that which other's find important.
Often has a poor working memory – meaning difficulty keeping track of everything one needs to do in a day e.g., pay bills, stop at the shop, get certain items when at the shop, etc...	Often has a great long-term memory – meaning this person is often good at remembering details of stories or events they <i>experienced</i> and embodied a long time ago. This lends itself well to working as a therapist and keeping up with clients' stories. But I really struggle with the admin (invoices and appointments) which is the working memory stuff – I am not 'one' with the admin.

A BRIEF REFLEXIVITY OF MY PROCESS

As a student I struggled to show my thought process in my schoolwork. You, the reader, may at times notice I don't always adequately guide you through my way of thinking. I try to do this, but it is not instinctual for me. The best way I can explain this is to say: I am often too *in* the process to see it objectively and therefore explain it to another person. Effectively I struggle to see the forest from the trees, and because of that I can't explain how I got from one tree to another. Is anyone else visualizing George of the Jungle?

Another common way symbiosis might present is when an autistic person expects someone to already know what they were thinking. It may be seen as ego-centric or lacking awareness of the other's perspective. This in turn may be responsible for the stereotype that autistic people lack empathy or theory of mind. Counterintuitively, a deficit in central coherence would lead to *extreme* empathy, as one is literally feeling the experience of another as if it is their own. For many autistics our volume is set on high, but to the outside observer this is understood as us lacking empathy. Misguided practitioners may then focus on getting us to turn the volume up, taking the already highly sensitive autistic person, and telling them their radar is broken and they need to work harder to tune into others. Essentially the autistic person's natural sensitivity is missed, and they are given the wrong message that they are insensitive.

UNINTENTIONALITY

Another common discourse on autism is that autistic people have no control over their neurology and can then act without intention. What is not acknowledged by the medical community or society is that *all* people lack control over their neurology. Non-autistics no more choose their way of being than autistics do (Manning, 2020). The dominant group pretends autistics are impulsive, lack self-control and the need for reminders or support belongs only to the Other. Again, this applies to all people.

The idea that there is a norm we should be living up to is the fundamental ethnocentric judgment. This leads to a paradoxical type of Othering, where the failure to recognize another's Otherness (their right to deviate from oneself or one's culture) leads to Othering attributed to personal failings for not living up to the imagined standard. If one deviates from the accepted order of society, that person will often be seen as 'disordered', as seen in Table Two below:

Table 2. Typical Behaviours According to Cultural Norms	
Typical behaviours	Atypical behaviours
Picking at one's nails or fidgeting when nervous.	Rocking back and forth to self sooth.
Publicly yelling at oneself when missing a shot during a sports game.	Publicly yelling at oneself when remembering or imagining something upsetting in the middle of town.
Not social distancing during a pandemic which calls for it.	Not keeping to the cultural norms of how much space people keep from each other at any time.
Driving too fast while singing along to music simply because it is fun.	Pacing back and forth while engaging in imaginary play because it is fun.
Jumping and letting out an involuntary sound when surprised by a loud noise.	Covering your ears and shaking when there is a sudden loud noise.
An adult swaddling oneself into a cosy sweater while drinking a to-go latte through a sippy-cup lid.	An adult participating in baby talk or enjoying sucking their thumb.

People who exhibit such behaviours in the typical category are usually not considered 'disordered' or 'unpredictable' (AKA scary) as these are activities shared by a large enough group and are therefore not scrutinized at a clinical level. At the same time, we judge the behaviours in the atypical category as non-sensical, involuntary and / or scary. We use phrases like "red flags" and "warning signs" (McGuire, 2016: 22). Primed with this fear-based discourse we then seek to 'treat' these people, protect them or protect others from them.

To challenge the assumption that autistic people need more help than non-autistic persons I think about the environment I found in any grocery store I visited during lockdown. On the

floor of the shops were taped arrows to indicate directions we were meant to walk and lines to mark the space we were meant to keep from others. Signs could be seen routinely reminding customers to abide by these rules and others, such as wear your mask, sanitise your hands and maintain a two-metre difference. If people were exempt from some of the rules, explanations might be asked for. There were verbal reminders of the rules - in the form of audio recordings routinely played over the speaker or directly from shop assistants. One shop I visited created a star-shaped badge for such a role, 'Covid Sheriff', which was given to employees whose sole purpose was to police the shoppers and enforce the rules. This heavy level of policing and cutesify-ing of the rules reminded me of measures which might be employed in 'special needs' classrooms or care homes. Measures reserved for persons who are considered to have the most 'severe' forms of autism. But we never storied the general public as 'extremely' disabled or incompetent or even 'mildly' disabled, despite the fact that for the majority of the population these reminders *were* needed.

Most people I came across in the shops did not stick to the two-metre rule. Some did better than others, but almost all, at one point or another in their shop could not help but break the rules 'just for a moment' when they spied the object they wanted to grab and needed to 'just squeeze by real fast' rather than wait or exercise the famed 'Executive Functioning'⁵. *But we don't talk about that.*

AUTISM IS (NOT) A LEARNING DISABILITY

Today we have many modern understandings of what autism is. A common misassumption about autism that I encounter in my life is that autism is a learning disability. It is not. It never has been. But I can explain where this misassumption comes from. In the 1970s there was a research program which only used samples of autistic persons who had IQs in the 60s. This created an understanding amongst many that autism *only* affected those with low IQs. But, as Hoekstra et al note, "intellectual disability is *not* part of the broader autism phenotype [and] the association between extreme autistic traits and intellectual disability is only modest" (2009: 534). Another reason this misconception continues to thrive is because in school settings it will

⁵ a concept which doesn't have a single originator but is frequently used in neuroscience to conceptualize how people manage their emotions and behaviours.

be autistic children with co-occurring learning disabilities who receive the most visible additional accommodations and segregation- leading onlookers, and perhaps even teaching staff, to stereotype autism as being part and parcel with learning disabilities.

Often, what I hear from parents is that if their child is academically capable then the needs related to autism are ignored by the school. But if the autism is pronounced then their academic ability is assumed to be low. My research participants discuss school experiences in Chapter Eight - which shows how the school as an institution is focussed on academic achievement. If we consider that this is the main remit for the school, then there is less need to acknowledge difference that doesn't distract from this objective, and it is useful to the institutions to segregate those children who distract from this remit. In some instances, this leads to professional agencies linked to the school to accuse parents (often mothers) of fabricated induced illness (FII) a term which means the parent has made up the child's illness, an accusation which then excuses schools and government from needing to make adjustments.

This is an issue which disproportionately affects autistic families (Gullon-Scott, 2022). I speak about this further in Chapter Seven.

HOW NORMATIVE BIAS PERSISTS IN THE RESEARCH OF TODAY

Using an autoethnographic method for her master's thesis, Sarah Grubb (2008) explored the ways in which professional literature assumes a disabling description of autism. I find this a valuable, albeit largely unrecognized, contribution to the discussion of how narrative shapes both social and professional treatments of autistic people. To illustrate this point, my don (the term 'don' is a word my don and I created to represent the non-binary child. We took the words daughter and son and combined them daughter + son = don.) invited me to share the following example: Recently my don was meeting with an educational psychologist employed by the NHS to do a cognitive assessment around Executive Life Function. At the start of this survey there was, in bold print, a warning that anyone reproducing the questionnaire without permission would be at risk of prosecution'. Immediately, my don pulled out their phone and took pictures of then entire document and began Whatsapping me.

Example Statement:

'I am not aware of how my behaviour affects or bothers others.'

Options for answers:

‘Never’, ‘Sometimes’, ‘Often’.

Many of the statements were subjectively phrased and didn’t try to be clear for the reader. In the above example, if the answer is ‘Never’ does this communicate to the clinician that the person doesn’t tend to upset others, or does it communicate to the clinician that the person doesn’t have *an awareness* of how others are perceiving them? Worryingly the non-autistic professionals get to decide what the answers to questions like the above mean.

Another statement was:

My work is *sloppy*. (Emphasis added)

Options for response:

‘Never’, ‘Sometimes’, ‘Often’.

My don and I shared the same initial reaction- which is that ‘sloppy’ is subjective. Boyle and Johnstone state that because of the subjectivity involved in assessing cognitive conditions “it’s not surprising, then, that terms like ‘excessive’, ‘inappropriate’ or ‘out of proportion’ are common in psychiatric diagnostic criteria (2018: 42-43). Okay - but still - Harvard educated adults (all the authors of this survey studied psychology at Harvard) didn’t pause to consider if asking children as young as 5, with autism, and *often*⁶ with co-morbid mobility irregularities such as dyspraxia, if their work was, ‘sloppy’ was detrimental to their self-esteem. While research is set up so that answers to the research questions can be tracked, they are not seeking to ask or record any emotional damage created through such questioning. Monique Botha carried out a survey of 195 researchers who studied autism. 60% of these responses were found to be ‘dehumanizing, objectifying or stigmatizing’ – with Botha noting that, “What is worse than I thought was how blatant a lot of the content was, which shows that, for [a] large proportion of participants, they did not consider the things they were saying to be problematic at all” (2021: 2) and “The mindset that underlies it also trickles down to study design” (2021: 2) As an example of the underlying bias of the researchers⁷ who created my don’s survey I offer other statements:

⁶ And I do mean *often*. I will expand on this further in this chapter.

⁷ Gerard A. Gioia, PhD, Peter K. Isquith, PhD, Steven C. Guy, PhD, and Lauren Kenworthy, PhD
www.parinc.com/Products/Pkey/24.

- 'I have outbursts for little reason.'
 - *If a person has an 'outburst' it will be a genuine expression of how they are feeling. This question is really asking whether or not social norms have been internalized by the child answering.*
- 'I get caught up in details and miss the main idea.'
 - *Whose main idea?*
- 'I get stuck on one topic or activity.'
 - *Isn't that what teachers are asking students to do all the time?*
- I don't know when my actions bother others.
 - *I note this statement hinges on the assumption that this young person does have actions that bother others. Also, this is a rephrasing of a question asked in five different ways elsewhere in the survey.*
- I get upset over small events.
 - *Who determines what is 'small'? Again, this is a repeated question. Again, testing that the person answering understands how others think, not what they feel about themselves.*
- I don't notice when my behaviour causes negative reactions until it's too late.
- I overreact.
- My eyes fill with tears easily over little things.

All of the above are asking the same thing. When an autistic person exhibits such obliviousness to how others are feeling, it is framed as 'lack of empathy', 'mind blindness' or 'ego centrism'. When non-autistics do this, it is not framed as anything at all. This is bio privilege.

So here is a statement I wrote:

When I highlight the ethnocentric thinking to professionals, they frame this as a flaw in my thinking because I'm autistic.

Options:

Never, Sometimes, Often.

I could not help but think the empathy we are encouraged to have as children, to consider others as we do ourselves, was absent in the clinical literature written by otherwise well-educated adults. How we are thought of shapes the care we receive, and this is reflected and

passed on in the language used in the literature that is used to train the next generation of professional helpers. Echoing this sentiment, in her blog McLaren writes:

The lack of awareness neurotypicals have — their blind acceptance of their world ‘the way it is,’ without concern for the needs of others — is called privilege in sociology. For example, a young white man who lives in Northern California in 2011 states that racism is no longer a problem is speaking from the ignorance of racial privilege. He may not be cruel or inherently racist himself, but from his social location, he cannot see or experience any direct racism; therefore, he mistakenly infers that racism doesn’t exist. Privilege is a form of mind-blindness that is, sadly, absolutely common in neurotypicals (2011, Empaths on the Autism Spectrum, part 1).

In his Neuroqueer website, Walker (2014) argues that, neurotypical privilege means that neurotypical people interacting with neurodivergent people — particularly when the neurotypical people in question are in positions of professional authority — have the luxury of never having to address or even acknowledge their own empathy deficits. For me, this principle is key. In my study, I seek to capture the inner subjective experiences of the autistic person and give a voice to the autistic person’s narrative as I collect stories from individuals on the spectrum.

What is being communicated by the survey is how non-autistics *see us*. I shared this document with a client of mine who has built a career around how ethical research should be conducted. She made several observations about the horrible way in which the survey was written, but more than that- she articulated what I find is a key point: *This survey only focusses on our behaviour*. It asks no questions about the person’s inner experience. This goes to my core argument about how trauma is created which I make later in this thesis. This questionnaire was produced in America by a private company called PAR inc. and sold with a booklet for over \$500.00. It has been bought and is distributed by the NHS.⁸ This is an example of how discourses which pathologize those who disrupt the smooth functioning of the institutions

⁸ www.parinc.com/Products/Pkey/24

become unquestioned assumptions that then form the basis for research that in turn goes on to become used in training, teaching young professionals and researchers how to regard these differences. Ashburn and Edwards offer the following passage to summarize this point:

autistic people are all too often scrutinized, studied, and talked about by people who aren't autistic themselves. It means that doctors, therapists, and educators are all too often taught outdated and harmful information.' (2023: 34).

TODAY'S CLINICAL TRIPOD OF AUTISM STEREOTYPES

As discussed earlier, in the DSM autism is distilled into three main areas of 'impairment': (1) a lack self-awareness and awareness of others. The clinical term for this is 'diminished Theory of Mind' and the mainstream understanding of this is, 'we lack empathy'; (2) 'depleted 'Executive Life Functioning Skills'. The mainstream understanding of this is that we lack self-control, are unpredictable, and likely to be volatile; and (3) we 'have a weak central coherence'. The mainstream understanding of this is that what is important to us is often irrational and wouldn't be important to others- meaning what distresses us is an irrational bi-product of our autism. Taking all of this together, autistic people are often seen to overreact, be prone to aggression and lack empathy. Gosh we are scary!

I assert that these *clinical* stereotypes have become mainstream stereotypes creating damaging misconceptions about autism.

Huw and Jones (2010) study "'They just seem to live their lives in their own little world': Lay perceptions of autism" aimed to explore the lay perceptions of autism in the general public. The study used semi-structured interviews to collect data from 24 participants who had no personal experience of autism and it found that many participants described individuals with autism as living in their own world and being unable to engage with others. They also perceived individuals with autism as lacking empathy and having limited social skills. In "Myths about autism: An exploratory study using focus groups", John, Knott and Harvey (2018) identified several misconceptions about autism among the participants. I grouped the myths identified into three sections which I detail below. This is that autistic people:

- Are Withdrawn

- ‘do not like to be touched’.
 - ‘are introverted’.
 - ‘are disinterested in social relationships’.
- Lack Theory of Mind
 - ‘are oblivious to social rejection’.
- Unintentionality – This could be linked to diminished executive life functioning or poor central coherence.
 - ‘are irrational’.
 - are high risk to themselves or others (Botha, 2022; Gillespie-Lynch, 2021; Jones, 2003).

SO, WHAT IS REAL AUTISM AND WHAT PERCENTAGE OF THE POPULATION HAS IT?

It is hard to say what percentage of the population is autistic. Attempts to collect this information have often yielded very different results. The World Health Organization currently estimates that 1 in 160 people have an autism diagnosis (Clay, 2017) while the Centres for Disease Control and Prevention (CDC, 2016) estimates that it is closer to 1 in 54. There is much debate around the possibility of over- and under-diagnosis and the use of labels in general. Diagnoses can vary greatly between geographical areas: the general awareness of autism varies by country and state, and cultural behavioural expectations of different places mean that some traits may be flagged in one country but not another (Pitney, 2015). This makes sense when considering the role cultural norms play in what we pathologize.

In “Understanding Stigma in Autism: A Narrative Review and Theoretical Model”, Turnock, Langley and Jones (2022) found that countries with a collectivist culture had a higher rate of stigma towards autism as fewer families were seeking an autism diagnosis for their children. One example of this was the non-clinical label of ‘border children’ in South Korea, in which children who would be diagnosed with autism in Westernized countries were not given formal diagnoses. As Turnock, Langley and Jones note, the “border children’ label ‘is partly driven by parental desire to avoid autism stigma, with the cultural importance of academic success supporting their child’s ‘normalcy’” (2022: 17).

John J. Pitney, author of *The Politics of Autism*, used the American census from different years in the early 1900s, divided it by 1/150 of the population (one modern estimate of the

prevalence of autism – assuming the prevalence is fixed and not increasing over years) and subtracted that by how many people were institutionalized in the same years. Even if all institutionalized people were autistics (which they surely were not), the figures still showed a significant portion of this 1 in 150 were not in institutions; they were out in the world somewhere (Pitney, 2015). This calculation suggests that many of the gaps between autistics and non-autistics are Level 2 and 3 gaps and a good amount of those people may have been passing in the world. They may have been: The quiet students; The rambunctious student; The student who stayed home and helped in the family business; The quirky clockmaker; The eccentric poet; The reclusive spinster. They may have been known to others as eccentric or different and yet their difference might have seemed within the range of normal at the time.

I am not sure there can be an answer to what percentage of the population has autism. We can only look at how many are diagnosed. How much credibility we give the diagnoses continues to be a point of contention while the broadness of the autistic spectrum leaves a lot up for subjective opinion.

THEY DON'T LOOK AUTISTIC

The modern discourse on how autism 'looks' which I hear the most is 'Autism is an invisible disability'. And yet people will frequently make the contradictory statement, 'They don't look autistic'. Suggesting that in fact people do expect to *see* the autism. I actually do believe autism can be seen at times. To me, it sometimes looks like a person in a state of hyper arousal, not comfortable in the environment. Sometimes it can look just the opposite: a person who is so completely at one with the environment that they lack any hint of inhibition. I expand on this further in Chapter Eight when discussing central coherence and symbiosis with one's experience. But I think the common expectation around seeing autism can cause difficulties. As Turnock, Langley and Jones note, "autistic people's 'typical' appearance coupled with their unusual behaviours may elevate stigma, with autistic behaviours understood as social deviance rather than reflecting an underlying difference" (2022: 84).

Not always, but many times, I believe people are expecting to see autistic traits that are often grown out of in older years, or more often the cooccurring conditions that might go along with autism. As Meyer comments "some areas of misinformation include that autism is characterized by symptoms of other conditions" (2003: 145). Most commonly, dyspraxia might

visibly present in someone who moves with less coordination. Dyspraxia is a condition that effects motor skills like handwriting and holding utensils, or overt motor skills like walking and sports. Oral dyspraxia can affect eating, speaking and facial expression. Visual dyspraxia can affect eye contact or the ability to focus on an object. Dyspraxia is more prevalent in people with autism; however, it is also worth noting that over 93% of people with autism were not found to have dyspraxia (Cassidy, 2016).

I was mindful of a few things when I read Cassidy's study: (1) it is the only study I could find seeking to look at the overlap between dyspraxia and autism meaning it would be nice if there was more research to look at in this area; (2) in the group of people without an autism diagnosis those with dyspraxia were found to have more autistic traits. This makes me question if they were undiagnosed autistics and if so, how does that affect the findings?; and (3) some people start to propose these are different conditions with similar traits and dyspraxia is being misdiagnosed for autism which is better known amongst diagnosticians. If that were the case that would change the findings completely. My thinking for now is that autism and dyspraxia likely overlap, but only a minority of autistic people have dyspraxia.

Because of the 7% overlap rate between autism and observable dyspraxia (and society's desire to *see* autism) many organizations use persons with observable dyspraxia to depict autism. I worry about the damage this does by sending a message to the general public that 'real' autism *should* be visible to the viewer. As an example, I use the below illustration:



Figure 3 Poster child for autism

In this image I note that the child has an uneven smile, their eyes don't look directly at the camera, it would seem their torso is angled forward with their head tilted up, which is common in dyspraxia. Although these features are subtle, they are pronounced enough to be captured in a photograph, unlike autism alone which cannot be captured in a picture. Again, I believe images like this cause the general public and professionals to develop a wrong understanding of what autism 'looks like'.

AUTISM: A THIN PRE-PUBESCENT BOY WITH AN INTEREST IN SCIENCE AND CLASSICAL MUSIC

My don walks in sees the picture in the above section and ask, 'Why is autism always portrayed as 9-year-old white boys with a penchant for maths and piano?'. I agreed that this seemed to be a common stereotype shown in TV shows like *Mercury Rising* (1998), *Parenthood* (2010) and *Touch* (2012) to name a few. But at the time they asked this, I didn't have the answer.

Years on, as I went through my research findings, I noticed a theme coming up repeatedly about intersectionality. This eventually lead me down a path of thinking that seemed almost too

obvious to have needed thinking about. I now believe the answer to their question is because prepubescent white boys were the most likely *product* to be scrutinized in Western society in the mid 1900s. My use of the word ‘product’ is intentional as they are coming down an assembly line needing to be sorted into a category of how they can best fit into our capitalist society. What is normal has historically rested on a bedrock of understanding that people are middle class, heterosexual, and white (Gkiouleka et al., 2018; Shildrick, 1997). Those who weren’t white and male didn’t need to be scrutinized as closely. In the mid 1900s girls were not expected to join the workforce in their adulthood and for that reason did not need to be classified or labelled.

In the first decades of autism research, white men studied white children, almost all of them boys. This became the most familiar image of autism. Traits that are not quickly associated with autism include: being older, female or darker skinned. What is less familiar is more threatening. Older autistic men are more concerning, reminding us that autism exists in the world and is not exclusively embodied by people who are not small and defenceless. Autistic girls might be seen as spoiled or petulant. Autistic women are often labelled with ‘borderline personality disorder’. People with darker skin and autism are more likely to be regarded as hostile and in need of heavy surveillance to reduce the risk to society (Poudrier, 2007). Darker skinned people are more likely to receive a diagnosis of schizophrenia which has a similar presentation to autism but currently includes aggression (DSM, 2013)

The thin pale prepubescent boy with a clear interest in science and classical music - activities associated with introversion and passivism - is the non-threatening autistic ideal. I would even go so far as to suggest that brown hair suggests more introversion than blonde hair. Even when autism is portrayed by adults the characteristics are often still brunette, pale, science / technology / math types, introverted, disinterested in women or, if interested it is in a non-sexualized way. Any sex is represented as a deflowering experience for the autistic person rather than one which suggests that the man fully understands and is interested in (e.g., *The Good Doctor* (2015); *The Big Bang Theory* (2007), *A-Typical* (2017)).⁹

⁹ This is a list of TV shows that have depicted an autistic man losing his virginity.

I do notice that some of our most popular autistic advocates are white, traditionally attractive, well-educated and articulate. I also note that when awareness of acts of prejudice or abuse comes into the mainstream it is often the most attractive, well dressed, well-educated version of that group that we look to as being unfairly treated. It is important to recognize that even within marginalized groups there are still many members who continue to be marginalized because they didn't fit into the accepted mould for their group. One of the biggest disparagers I find is that of class and education. When looking for existing literature which might come close to addressing my research question, the first work I found was by Melanie Yergeau, an autistic researcher and assistant professor of English at Michigan University. In *Authoring Autism: On Rhetoric and Neurological Queerness*, Yergeau writes:

as a white autistic who has attained considerable education – I am a professor who can, even if only infrequently, access reliable speech – I write this book with great trepidation, and resignation, that autism politics routinely reward those who are multiply privileged (2018: 5).

Coming back to my earlier section, "Pathologizing Abnormal", in which I explore the beginning of the DSM as a way to determine who was fit to work, Ashburn and Edwards tell us that "people labelled as 'high functioning' are those who can contribute to capitalism. They can usually speak, conform to social norms, and are allowed to achieve limited power. As Ashburn and Edwards note, "those labelled as 'low functioning' do not contribute to capitalism and are deprived of power and autonomy" (2023: 41). Many people take the view that those who can manage with fewer adjustments and are granted what is seen as a more privileged position within society do not have 'real autism'. It occurs to me that this is not dissimilar from the idea that a person of mixed race cannot legitimately claim membership to either group. Some will say that a mixed-race person is not entitled to the acknowledgement they might receive as a member of a disempowered group, but nor can they fully enjoy the privilege of being a member of the dominant group.

I wonder if social media and the neurodiversity movement existed 200 years ago if there would have been families arguing about what was 'real dementia praecox', claiming that some people had too mild a form and that their child had the 'real' or 'severer' version? To challenge the discourse that 'high functioning' autism is not real autism, my son shared with me a YouTube

video created by Ilyssa “Illy” Levy. Illy uses the analogy of vision impairment to discuss degrees or frequency with which an autistic person might need support as she argues “You may need glasses to see when you’re reading meanwhile, I need glasses to see anything at all. But that doesn’t mean you’re faking it” (Illymation, n.d.).

SUMMARY

On one hand, the ‘biomedical model’ from the 1940s perceives autism as a cognitive disorder or disability (Baron-Cohen, 2000; Frith, 2010; Kanner, 1943, 1949). On the other hand, the ‘difference model’ interprets autism as a distinct way of being, arising from differently wired brains (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Emerging from the ‘difference model’, Runswick-Cole (2014) notes that the neurodiversity movement relies on a biological framework that people with autism have differently wired brains. The neurodiversity movement maintains that this distinctive way of thinking is not a disorder or illness. Labelling it as such can lead to discrimination against autistic people and their families. In the following chapters I look at how this perception of autism as an illness might lead to acts of discrimination.

Citing, Campbell (2009), Baker-Rogers notes that “authors have argued that today’s society desires ontological security or confidence in the nature of the social world and this concept is challenged by disability” (2017: 47). The idea that there is a norm we should be living up to is a fundamental ethnocentric judgment. This leads to a paradoxical type of Othering, where the failure to recognize another’s Otherness (their right to deviate from societal standards), leads to Othering attributed to personal failings for not living up to the standard. If one deviates from the accepted order of society, that person will often be seen as ‘disordered’.

Over the years, behaviours that don't fit societal norms have often been labelled as ‘naughty’ or signs of mental illness by the so-called 'experts'. Minority groups which express upset over

their societal treatments have been diagnosed with mental illnesses. Runaway slaves were diagnosed with drapetomania. Feminists were diagnosed with hysteria. Homosexuality was listed as a mental disorder until the late 1980s. Whilst these past acts are widely recognized as psychiatric discrimination, they are still happening today. Black men are two and a half times more likely to be diagnosed with schizophrenia than white people. Borderline Personality disorder has replaced the term hysteria as a label that means emotional instability and is applied to women three times more than to men. Gender dysphoria is still listed in the DSM as a mental illness, but 'gender dysphoria' as a clinical label is only given to members of the LBGT+ community, despite the fact that almost all people experience gender dysphoria in one form or another: The man who is going bald but wishes he wasn't is experiencing gender dysphoria. The woman who doesn't want facial hair but has it is experiencing gender dysphoria. But people who identify as their birth gender aren't given the diagnosis of gender dysphoria because their displeasures at how their body is expressing gender seem normal to assessing doctors.

Like the groups above, neurodivergent people are often seen as having deficiencies, with the assumption that being neurotypical (having typical brain function) is the best way to exist. Unfortunately, front line professionals such as teachers, social workers, nurses, and doctors often rely on the 'experts' and what they consider 'common sense,' to define normal behaviours and rarely question social biases which shape such 'evidence'. This can give rise to compliance therapies using coercive methods to make autistic individuals and/or their families stifle their authentic way of being to fit in with social norms.

In early life these factors can lead to children hiding their real selves away, so they are not allowed the space needed to develop, get to know themselves or understand their feelings. They then become an adult who doesn't know themselves, is afraid of their feelings and how others will perceive them. They are often worried about whether they are getting things 'right' or 'wrong' to the point that they experience freeze and flop responses when they're put on the spot. These are some of the effects my research participants described, and I find these descriptions similar to the descriptions of complex-PTSD¹⁰ so much so that I have created a

¹⁰ I explore complex-PTSD further in later chapters.

chart comparing the supposed 'autistic traits' to well-known trauma responses.

- Meltdowns / Fight or Flight: An instinct to keep us safe by fighting against a perceived threat or withdrawing ourselves from it.
- Mutism / Freeze: Becoming immobilized or speechless when our body fails to execute a response. I find that this can be due to social conditioning which has overridden our instincts towards fight or flight.
- Masking / Fawn: The attempt to make ourselves charming to anyone who has the power to harm us. This may simply be emotional harm through social rejection. Again, this trauma response can be due to social conditioning which have overridden our instincts towards fight or flight.
- Meh / Flop: Flop is similar to Freeze in that we become immobilized, but flop happens when our body has gone into a state of hypo-arousal rather than hyper-arousal which is associated with Freeze. Flop often happens when the individual has experienced repeated traumas to the point that the nervous system is so accustomed to the act of releasing calming chemicals after a threat that this process speeds up and a person goes into the flop state much sooner than is helpful. Often leaving them vulnerable to the ongoing threat. It may also be part of social conditioning in which the individual has learned that they cannot prevail against the threat and thus they give up much more quickly.

Like the examples I used of oppressed groups responding to discrimination, the trauma responses are often seen as evidence that *autism* is the cause of suffering. When Meltdowns, Mutism, Masking and Meh are referred to simply as traits of autism we are ignoring that these are actually renamed trauma responses. Common headlines that further the discourse that autism is the problem include phrases like: 'The warning signs of autism'; 'The autism pandemic'; and 'How to help children with autism'.

As a society we need to stop and confront the bias that leads us to question someone else's neurology and way of being, while also recognizing that such questioning and attempts at

‘correction’ inflicts lasting emotional damage. We need to see the warning signs of harm created by normative bias, end the pandemic of compliance therapies, and help children with autism feel entitled to take up space and get their needs met.

PART TWO: PERMITTED TREATMENTS

CHAPTER 4: HELL: CIRCLE 9 $\frac{3}{4}$

The treacheries of these souls were denials of love ...so are they furthest removed from the light and warmth...As they denied all human ties, so are they bound only by the unyielding ice." (Ciardi, 1957: 248) Notes on Dante's 9th circle of hell.

In Dante's "Inferno", the deepest level of hell is reserved for those who broke the trust in sacred relationships. The ninth circle is then divided into quarters to further categorize the seriousness of the types of betrayal.

1/4 First: The betrayal of one's family.

2/4 Second: The betrayal of one's government or the institution.

3/4 Third: The betrayal of those one has agreed to care for.

4/4 Fourth: The betrayal to one's lord.

If we are to consider how Dante ranked such sins, it would seem that the betrayal of someone dependent on us for care is worse than the betrayal of the institution. Psychologists Isaac Prilleltensky and Geoffrey Nelson define power as "the opportunity to fulfil or obstruct personal, relational, or collective needs" (2020: 7). This understanding of power highlights that those we rely on for support wield significant influence in our lives, leaving a profound impact. There is a particular trust that exists when someone is paid to support you. The a-symmetrical power dynamic is part of that trust, but so is the dependency on the care provider's awareness of the client's needs, neutrality, and professionalism, which simply doesn't exist in strictly social relationships. This speaks to a different type of privilege. The sort of privilege one refers to when they say, 'That is privileged' - meaning it was a product of a sacred relationship in which trust is paramount. In social relationships sometimes that trust exists and sometimes not, but there is no rule for it. With professional helpers, trust is given based on the privilege that relationship carries. This is perhaps why Dante regarded betrayal of those outside one's family as worse offences.

Those who embody biological traits of normality hold the highest societal positions, referred to by Foucault (1982) as possessing 'Bio power'. This status enables them to scrutinize and discipline those who deviate from the norm. Notably, individuals with bio power are not only those conforming to societal ideals but also those within social or healthcare roles wielding recognized authority over the body. Unfortunately, the power of these 'experts' doesn't rest on competence but on the confidence, they exude, often derived from society's respect for certain biological attributes (often being male, white and tall), scientific language, and an education that itself is built of normative bias. Boyle and Johnstone (2018) emphasize that the expert is then granted an ideological power, in which their word is often taken as fact without the same scrutiny that is applied to the non-expert, the individual or the parent or caregiver.

A friend of mine tells me that things like what happened to us aren't supposed to happen to *people like us*. But they do. The abuse and dishonesty we suffered is not uncommon and transcends all classes. And often it can be much worse than what we went through. Instead, I would say 'people like us' (nice, middle-class, educated) don't speak about it. We don't want to 'air our dirty laundry in public'. We are afraid we will not be believed. And that is why this behaviour can continue: because people like us are scared and want to protect the reputation we have as the 'nice family'. I tell my story - our family story - for this reason. With great reservations I anonymize the professionals involved.

I write about professionals throughout this thesis, and in almost every passage they are nameless and faceless. The term 'professional' automatically implies something not personal - but how we feel about professionals in our lives can be *deeply* personal.

The doctor, who I will call Dr Harris, was someone I cared for deeply. I met him in 2008. I was 31, my son was 6 and was about to receive a diagnosis of autism. At the time we were moving house and as a consequence would have been in a different catchment area from the practice, meaning my son would have to start his two-year autism assessment over. I was desperate to get the diagnosis in anticipation that this would help him at school. The doctor made it so we didn't have to move to another clinic or start the process over. He had the power to change something for us, and he did. From the start he was my hero.

Despite this gesture of kindness, he wasn't *always* nice. I was occasionally taken aback by some of the things he said over the years as he worked with us. He was sometimes kind, but often distant, neither kind nor cruel, just reserved. He was bad with returning calls or following up prescription requests or referrals for additional therapies. He had the power to determine how quickly my children got their medication, how soon they could have their next appointment with him, whether he supported my requests with their schools. The smallest gestures of kindness, or just doing something my children needed, made him my hero. Whenever he was distant or failed to follow up with things, we needed I made excuses in my mind. In his work, *The Birth of the Prison*, Foucault (1979) explains how the medical doctor gained a position of power within society. The doctor was seen as a benevolent father figure, whose potency was fuelled by the societal belief that he was all knowing and good. The fact that Dr Harris's demeanour was so conditional made his response to me all the more important. More and more I wanted his approval of my parenting and life choices in general. And when he signalled his approval by lighting up, smiling, leaning in, that was a dopamine hit. When he signalled his disapproval by going quiet or not looking at me, I felt ashamed. I couldn't see this as manipulation. It would take years after the fall out to look back at it objectively.

One morning at a parents' coffee meetup I overheard another mum criticizing Dr Harris for calling social workers on her. My reaction back then was to instantly discredit her. For me I couldn't imagine him taking safeguarding steps without good cause. I imagined the parent speaking was in denial about something. Surely there must have been more to it. That was my view of the world back then. Doctor's good. People who had social workers involved in their lives suspect.

A decade after meeting Dr Harris, in March 2018, my husband and I had an appointment with him. During this appointment we shared that our son was rummaging through another family member's room when they weren't around, and that this behaviour was becoming a problem for everyone involved. Even though Dr Harris had no sage advice to offer, he provided reassurance that we were doing all that could be expected. He told us we just needed to 'keep firm boundaries in place' and that this was 'normal' teenage behaviour.

Three months later Dr Harris was at my son's school discussing another child and another

situations wholly unrelated to us. As Dr Harris was about to leave the meeting, a member of the school staff mentioned my son. Dr Harris, who did *not* have my son's notes to hand, responded with a fabricated account of that last meeting. According to school he had said that my son watched a family member in the restroom. I only learned about this exchange when social workers arrived at my door that evening wanting to interview my children about perceived risk within our home.

From the moment I answered the door to the social workers I was in a state of shock. School was closed, the doctor's office was closed. There was no way to straighten this out in that moment and the social workers expected me to simply stand aside and let them question my children right then and there, implanting in their minds scenarios of abuse they never would have considered otherwise.

"Institutionalising Parent Carer Blame", a research report produced at the School of Law, Leeds University, describes how families often reported that such "visits could take place with little (or no) notice and that parents were often placed in impossible positions feeling that any objections to professionals intruding on their private life would be treated as a 'red flag'" (Clements and Aiello, 2021: para. 4.12)¹¹.

If I objected and it was seen as a red flag which I'm sure it would have been then the intrusions into our lives would have been worse. I prepared my children for the questions they would be asked. I did this by giving them the context of what had been said and telling them to simply be honest. It was a horrendous evening.

The next day, I phoned the doctor and told him about his mistake. He paused to check his medical notes and then admitted that he *had* indeed made a mistake. He apologized and promised to contact both the school and social services to correct the information. I breathed a huge sigh of relief. I felt completely reassured and trusted that he would do what he had promised. I even felt a premature sense of vindication as I waited for the school and the social workers to apologize for their misguided intrusion into our lives. Unfortunately, as the weeks went by the doctor never told anyone about his mistake. His apology was private and just for

¹¹ The report can be downloaded at www.cerebra.org.uk/download/institutionalising-parent-carer-blame/

me. I had told the school and social worker about my conversation with the doctor and told them a phone call would be forthcoming, but the lack of any such phone call only served to discredit me. No one else had any reason to believe the doctor had made a mistake.

I emailed a few brief polite emails. I didn't want to be annoying. After weeks turned into months, I finally followed up with a phone call to the doctor. 'This seems to be a theme with you.' He said curtly, adding, 'You're overly concerned with the accuracy of the information because you're autistic'. Then he said, 'If you're not satisfied with my work, you can complain. It's helpful when people do that because then *everything comes out*' (emphasis indicated by his tone). I understood the message - things would be said that would humiliate and discredit me.

Central to Foucault's analysis of power relations is the concept of the 'docile body'. In *Discipline and Punish: The Birth of the Prison*, Foucault (1979) uses the term 'docile bodies' to refer to self-policing individuals who have internalized a fear of disciplinary measures and therefore more readily conform to institutional expectations. Foucault emphasizes that disciplinary power does not solely rely on physical coercion but a fear of emotional distress such as shame. Protecting the power structure is the concept that in order to be seen as good, responsible or rational amongst members of disempowered groups, one must be obedient to those in positions of authority so as not to *further* burden those who have humbly taken on the role of provider and protector. Below I include a picture of how suffragettes were portrayed when demanding the right to vote. The discourse is that they were irrational, selfish and infantile.



Figure 1 Anti-suffragette Propaganda

This image shames women for their refusal to be quiet about the injustice, and I can imagine that there will have been other women who obediently internalized such messages angrily telling us we were being irrational. Invalidation was possibly the most difficult part of everything. I started to question myself. Regarding such self-doubt Johnstone and Boyle write:

More generally, invalidation can lead to lack of confidence in your own views; ... self-doubt, self-silencing and self-blame (Am I oversensitive? Should I have said something? Was it all my fault? Did that really happen?). People can be reluctant to report even criminal acts because they might not be believed. And if your views and experiences are not validated, or are subtly or forcefully invalidated, then it can also be difficult to give a clear account of them, reinforcing doubts about the worth of your perspective (2018: 91).

The “Institutionalising Parent Carer Blame” report states that the tactics of humiliation and intimidation are routinely used against families of neurodivergent children to conserve government and institutional resources. In this process, a discourse is developed to support the idea that family members seeking support are the ones causing any problems. Similarly, Judith Herman writes the following about how people seek to escape accountability for their harmful acts:

In order to escape accountability for his crimes, the perpetrator does everything in his power to promote forgetting. Secrecy and silence are the perpetrator’s first line of defence. If secrecy fails, the perpetrator attacks the credibility of his victim. If he cannot silence her absolutely, he tries to make sure that no one listens (1994: 67).

Whilst waiting for the promised corrections, Dr Harris wanted to make a referral to forensic services for my son to be assessed for ‘concerning behaviours’, which sat on a foundation of uncorrected fabrications. My husband and I both felt this was absurd. No way would we consent to this, particularly when there was still misinformation written about our son. There was no reason to think that new professionals would have a correct understanding of our son.

When I refused the forensic referral for my son, Dr Harris told me it was *his* decision to make. As a psychotherapist I knew this to be incorrect. The same laws that governed me governed him. I was shocked that a psychiatrist, who is held in a much higher regard than a therapist, wouldn’t know the laws around consent. I communicated this to Dr Harris and was clear that

I found his ignorance in this regard quite scary. When he finally confirmed for himself that we *were* entitled to refuse treatments, the coercion started. Dr Harris suggested that our refusal to consent could hinder our son's support at school, lead to him being hospitalized and seen as us deliberately trying to hinder his healthcare needs, a type of parental abuse.

Two instincts were at war. One was the instinct to protect my child. The other was the instinct to be seen as rational by all the professionals who will have been listening to his account of how I was behaving. Were I only reading this story, rather than someone who had lived it, I would have said there was nothing to think about - '*Obviously... protect your child. End of...*' - but sitting in a room with the calm confident doctor telling me that I will be seen as a bad mother and my child will lose support if I don't agree to his recommendations, I doubted myself. This dilemma tortured me for weeks until eventually, I gave in and consented to the referral. I thought, my son will be scrutinized, and it will all be over. We just have to wait for the professionals to do what they want, and it will all be over.

A DIGRESSION TO CONSIDER POWER AND THE POWER OF OTHER PEOPLE'S PERCEPTIONS OF US...

Foucault's (1982) argument about internalizing authority and power is a key concept in his theory of power and knowledge. This internalization of authority contributes to the perpetuation of prevailing norms and institutions in society. Stopping at a red light when no one else is around illustrates this concept well. In modern societies, traffic lights are established as a mechanism to regulate and control traffic flow, ensuring safety on the roads. These norms are established and reinforced through legal systems, educational institutions, and various forms of societal conditioning. Even when no one else is present at a red light, an individual who stops is displaying the internalization of authority.

I grew up in a rural area of Texas. In the village near my house there was one stop light. It was needed because the town's population all did the same things at more or less the same times: the school run, the drives to and from work, church on Sundays. But outside of these times the village roads were extremely quiet. Late in the evening or very early in the morning the light would still be changing from green to yellow to red with no one around to take notice. If, during these times, I would come to a stop light, and I could see far into the distance that there was no one was coming from any direction, I would still sit there waiting for the light to go green. I

would have had a bodily feeling of dishonesty or immorality if I were to drive through a red light. In this instance my sense of immorality would not have been due to an idea that I am putting someone in danger, but instead simply that I am going against authority. Or that anyone watching would think badly of me. I didn't articulate these fears to myself. I didn't question or reflect on why I stop at red lights when there was clearly no risk of harm. I just knew that I did so - and those who didn't were obviously bad people.

This is how internalized ideas about right and wrong behaviour work in our bodies and minds. We do not often stop to reconsider the rightness, wrongness or relevance of the rules that we have internalized. I would say this is also how bias and prejudice become internalized. Our world perspective is just something we grow up with - it's just 'common sense' - which all reasonable and good people agree with.

THE FORENSIC REFERRAL

A week before I was due to sit the exam for my MSc in psychotherapeutic counselling in October 2018, a copy of the forensic referral, as written by Dr Harris, arrived in the mail. The referral was *horrendously fabricated*. This was the second time the doctor had fabricated information about my son, and he still hadn't corrected the first fabrication which was documented as a safeguarding concern. There was no evidence to support my claim that the first piece of falsified information was false. There was only a paper trail from the school, social services, and the doctor, painting my son as high risk. Because of this, I felt no immediate reassurance that I would be able to evidence the falsifications in the forensic referral. My trust in all professionals was breaking down.

For my son's privacy, I leave out the details of what was written about him. It is somewhat similar in nature to a news story in the *New York Times* (Boniello, 2023) about a 15-year-old autistic boy named Terrance O'Connor who told a teacher at his school that he identified with the school shooter in the movie *Heathers*. Later that day the teacher phoned the police to raise her concerns and the boy was arrested on suspicion of terrorism. The father echoed words I have said about my son, stating that his son was gentle and that this experience of intrusion and accusation from authorities has traumatized him. He asserted that before the arrest his son was not *completely* broken but after it, he was. Like my son, Terrance was dark skinned and robust in build. I could imagine that both played a part in the way they were treated by

authorities.

I read the comments left by other readers of this news story. At first, I was heartened to see that many people were on Terrance's side, but further in the comments there were people who argued in opposition. For example, one commenter, TM wrote "You so [sic] understand at least two mass shooters had Autism" (May 28, 2023, comment on Boniello 2023). This comment seemed to suggest that autism should be seen as a risk factor. But research shows that autistic people are less likely to be perpetrators of violent crime than the general public (Allely, 2017). What TM does not state in their comment was that every year there are hundreds of mass shootings recorded in the US, and they also did not state what years they were looking at. For simplicity I looked over the last five years and since 2018 there have been *more than 2000* mass shootings recorded in the US (Boschma, 2022). If we were to accept TM's claim that 2 of the mass shooters had autism and say that they were shooters in the last 5 years, then this would mean that .1% (1 in 1000) of shooters had autism. And yet, the World Health Organization believes that 1% (1 in 100) of the general population has autism (WHO, 2023). This would mean the autistic person is *ten times less likely* to be responsible for a mass shooting than a non-autistic member of the public.

BACK TO THE REFERRAL

Many such professionals (not all) seem to have sought roles as wardens, rather than supporting professionals. Even the 'wardens', may call what they do 'support' even though these are often acts which deny autistic individuals the same trust and autonomy afforded to non-autistics. This intense segregation, bias and scrutiny make the risk of falsified records more terrifying to the individual being written about.

As I read the referral about my son, I felt cold slime run down the back of my neck. My stomach went queasy as I gripped my desk for support. That was the first time I had felt these sensations in in this situation. Previously I might have only been aware of such feelings on a scary ride or during bad turbulence on an airplane. This physical sensation was likely caused by the release of adrenaline (epinephrine) which causes blood vessels to constrict, redirecting blood flow to vital organs and muscles, which can make the skin feel cool, preparing the body for 'fight or flight'. But as is often the case in contemporary society, the stresses our bodies identify and

respond to are not immediate physical threats but psychological threats. Our bodies prepare to run or fight, but our animal instincts are suppressed, and our nervous system is left in a hyper aroused state with no way to process our feelings. Those noxious feelings would come back many times over the next five years as I went through complaint and court processes.

I sent previous emails from my son's school contradicting the statements the doctor had made in his referral. Dr Harris responded telling me that I was 'too emotional' and he could see no point in discussing the matter with me when I was like this. After ten years, those were his last words to me. I was shocked and heartbroken. It took me a few weeks to start the complaint process. I was waiting for the person I thought he had been to emerge and say he was sorry and make corrections. But as I was waiting, I was leaving my son vulnerable and for that I felt stupid and ashamed. I finally filed my first complaint with the NHS. I only wanted an apology and corrections. But the doctor was right. The internal investigation carried out by the NHS focused on me as a parent, and never addressed the issue of the falsified information about my son. The investigator, Tracy Blackburn (a pseudonym) took small pieces of factual information from our pasts and twisted them into a false narrative of our lives. Examples included stating that my son had assaulted students at his high school and kept making verbal comments to the students in question. Another example was writing that I had *locked a member of my son's school staff in my house* when in reality we had had an argument in my front garden. She used other, unrelated details from my life, to portray me as a 'scorned woman' with a vendetta against men.

THE EXTRAPOLATION AND EXAGGERATION TECHNIQUE

Taking small parts of the truth and twisting or exaggerating them makes it harder to deny that an event didn't take place. If you are being honest in explaining that a small part of something *did* happen (e.g., 'Yes, I yelled at a member of the school staff back in 2015. But no, I didn't lock her in my house'), then it can sound as if you are downplaying an event. The people who use this Extrapolation and Exaggeration technique¹² to create a negative picture of a child or their family, know how hard it is to have these types of falsifications corrected when they contain an *element* of truth. They also know that if they are proven wrong, the professionals can claim it was just a 'misunderstanding' or act as if it is a small detail. This makes it an advantageous

¹² So named by myself.

technique with low punitive risks for them. I believe this technique is intentional and used strategically for these reasons.

The term for this tactic is often referred to as a 'disinformation attack' (Bennett, 2018), which is the intentional act of confusing, distracting or manipulating people who are reading or hearing the information. Foucault (2018) explains how people are 'storied' by professionals and institutions are 'games of truth' in which the person being spoken about has little say in the story being created about them. Whilst the stories may be constructed of facts and used for benevolent reasons, they can also be fabricated and designed to punish the subject and protect the institution from scrutiny (Foucault, 1997). Another way to understand this is that most recorded information about service users will be accurate and benign, but if the service user challenges the 'wellbeing' of the institution, information about this person starts to be more creatively and intentionally constructed. This storying process involves the professional using their power to create accounts that will be treated as fact by other professionals and institutions in line with the multi-agency approach. This is also referred to by Boyle and Johnstone (2018) as 'ideological power'. I highlight this type of power in some of the narratives offered by my research participants in later chapters.

Everywhere I turned in seeking justice, I was immediately discredited because of what had been written about us by Ms. Blackburn. I was portrayed as the dysregulated woman who was overreacting. In contrast, Dr Harris always presented as well-regulated, confident, and soft spoken. There was very little reason for him to *become* dysregulated. He and his family weren't under threat. At that point in time, it seemed like everyone believed and supported him. He had no reason for fight, flight or fawning. As autistic people we are easy to discredit. We are presumed to be irrational. And I believe Ms. Blackburn knowingly relied on this societal stigma to protect the doctor who hurt my son.

Shortly after writing her document, Ms. Blackburn left Northumbria Trust and took a post with Cumbria NHS Trust as team manager for their Mental Health Department. A newspaper article was written about the good works she planned to revamp their department. She was quoted as saying: "We have a clear and shared vision to reduce the stigma surrounding mental health in the county and want young people to know it's ok to ask for help and support when they need it" (Northumberland NHS, 2020).

This is an example of what a former client of mine would call a ‘token statement’. Token statements are statements that reflect politically correct discourses, such as ‘we must reduce mental health stigma’, ‘we are prepared to make adjustments’ and ‘we follow the social model of medicine’, but which are then coupled with behaviours that contradict such statements. She absolutely used the fear and stigma associated with psychological labels when she created a disinformation attack against myself and my son. Foucault's (2018) explores the complexities and contradictions present in discourses within society. He emphasizes that power relations and knowledge are closely intertwined, and dominant discourses can both produce and conceal contradictions. Foucault's (2006) ‘archaeological’ approach to knowledge seeks to uncover the underlying historical and social conditions that give rise to specific discourses. He analyzes the rules of formation that govern what can be said and understood in a particular context. This approach reveals the contradictions within different historical periods and exposes the power dynamics behind various discourses. Alex Fox, CEO of Shared Lives Plus calls out such smoke screens.

Changing the language used within organisations and systems can often be a substitute for changing behaviour and beliefs, with the new softer-sounding language adding a coating of irony to unyielding bureaucracies (2018: 25).

Despite Ms. Blackburn’s efforts I would eventually receive *some* validation from the GMC, who wrote the following:

There is information to suggest that Dr Harris failed to correct information ... and there is nothing to suggest that he sought to correct this information. He had initially admitted making a mistake in relation to the first error, but in October 2018 had not acknowledged that he had made a mistake, which undermined Mrs Uher’s position. (GMC, 29 June 2020)¹³.

Despite this response, no further action was taken by the GMC; but a month later, the doctor ‘retired’ from the NHS and Tracy Blackburn left the Trust for her new position. My son was then offered an out of court settlement for the fabrications in the forensic

¹³ This is an excerpt from the findings of the GMC regarding my complaint.

referral written about him. Despite these turns of events, Northumbria NHS refused to acknowledge the fabrications they had written in the investigation paperwork. I brought this to their attention, and they simply would not respond.

I was on high alert for months. Strangely, it was the Covid-19 pandemic that offered some relief from this fear. The world went on lockdown, which meant that the professionals were more removed from our lives. Essential workers were more overstretched than ever before and couldn't spend time investigating families that weren't really at risk. During this time, and with the help of a lawyer, I was finally given access to the 'investigation' paperwork. This is when I discovered the additional fabrications written about us during the investigation. At the same time that I discovered Ms. Blackburn's document, I also discovered correspondence between people I had never heard of discussing me and my family by name. In one exchange, a doctor we had never met expressed disbelief that my children *hadn't* been removed from our home. From this doctor's perspective, what she had read about us in the investigation documentation *had* to be true. The fact that no steps had been taken to remove my children truly baffled her. She couldn't understand how social workers could be so involved with our family and *not* do something to protect them from me. I had no idea who this woman was. I had never heard of her, and we had never met, but reading her words made me very sad. She was convinced that my children were at risk from *me*. It felt odd to me that someone I had never heard of, who had never met us, felt entitled to read about me or my family or have opinions about us. I couldn't understand the mindset of a person who hears or reads private details of another person and feels OK with that. Professionals can be so conditioned to believe they are entitled to peer at us and tell stories or listen to stories about us that they don't get the revulsion most people would feel when gossiping about someone. This reminded me of a quip from comedian Brian P. Cleary, "It's not technically gossip if you start your sentence with 'I'm really concerned about,' (fill in the name of the person you're not gossiping about)" (2010: 2). We all experience this behaviour as a violation. The sad reality, from my perspective, was that this doctor and her colleagues were far more likely to harm my children than me. The fact that I was simply doing my best to keep my family safe, and how terrifying this was for me, was clearly unfathomable to her - and she kept scrutinizing us at her leisure.

I meet professionals who recognize that such treatments can be deeply intrusive and harming to the families. The ones who acknowledge that there is systemic discrimination and

traumatizing oppression are frustrated with the system for hurting families and are hopeful that one day these families will recognize the ways in which they are different from the other professionals who do harmful things. They continue inserting themselves into our lives, discussing us with benevolent concern, waiting for us to realize they're different from the last group scrutinizing us without our consent. I used to take clients who had been ordered to have therapy from the courts. I wanted to work with them because I felt I was more likely to understand them than other therapists. I thought, because I recognized the systemic oppression, the unfair power dynamics and many different types of discrimination that frequently factored into such orders, that I would be the therapist they needed. The problem was that regardless of my intentions, my clients were not asking for, or consenting to, therapy. I was not an effective therapist in these roles because there was no trust. How could there be? I was getting paid to execute something which had been forced upon them.

MULTI-AGENCY APPROACH

Jeremy Bentham, an English philosopher and social theorist who lived in the mid-1700s, came up with an idea for a prison system called the Panopticon which allowed for monitoring a large number of prisoners with as few guards as possible. The layout consisted of a central tower where the guards would be stationed, surrounded by a circular building containing prison cells. The unique feature of the Panopticon was that each cell faced the central tower with an open side, covered only by bars. This meant that the guards could see every prisoner in their cells at all times. Because the tower was at a distance and the windows the guards looked through were smaller the prisoners couldn't see the guards inside the tower. This arrangement created a psychological effect on the prisoners who never knew exactly when *they* were being watched. This constant awareness of possible scrutiny led to the prisoners internalizing the rules and expectations of the guards (Wikipedia, 2023).

Foucault further developed Bentham's concept of the panopticon to illustrate how it represents a form of social control that goes beyond just the prison system. In Foucault's work from 1970, he argued that the panopticon serves as a symbol for the broader control mechanisms present in everyday life for all citizens.

According to Foucault (1970), individuals exist within a network of societal expectations. What is important to understand is that each person's role within this network becomes ingrained in

their body and mind. As a result, individuals internalize these expectations, leading to self-discipline. In other words, the panopticon becomes a metaphor for how people regulate themselves in society. The constant awareness of being observed and evaluated by others influences individuals to conform to social norms and expectations. This self-discipline becomes an integral part of their behaviour and mindset, shaping their actions in everyday life.

From the position of the professional, it may seem that my thesis should focus on one specific profession or at least one field. However, from the position of the service user - the position I am concerned with - most professionals appear to be united. The multi-agency approach creates the same effect on families that the panopticon had on prisoners. This creates not just a worry about the scrutiny and judgment of authority, but also a sense of being watched like an animal in a cage - deprived of privacy at all times. Heavy surveillance and lack of control over one's own life is dehumanizing and having one's humanity destroyed is the definition of trauma. Those who participate in the observation of others are participating in inflicting institutionalized trauma.

Outside of what was happening with my family, near where I lived, a young autistic woman named Zoe Zaremba took her own life because of the treatments she received from members of staff at Tees, Esk, and Wear Valley NHS, who described Zoe as having borderline personality disorder (BPD). This was not an official diagnosis for Zoe; rather, it was speculation which had made its way into her medical file and influenced the way staff then saw and treated her.

What stood out for me in Zoe's story was: (1) The label of borderline personality disorder was never discussed with Zoe. I can't think of another area of medicine where a diagnosis would be kept from the patient; (2) Zoe found out this term had been applied to her by reading her medical notes. She didn't agree with this label - it totally contradicted her sense of self, something which many experience as trauma. I explore this further in future chapters when it is brought up by my research participants; (3) Like schizophrenia, BPD is subject to stigmatization more than autism, which led to the dynamic of Zoe being treated differently by staff; and (4) *Even though it was agreed that this was an inaccurate label for Zoe, the Trust did not remove it from her medical records.* Therefore, it continued to reinforce Zoe's lack of control over how she was perceived and treated, even though she voiced her distress. In other words, they *knew* Zoe experienced this label as distressing, yet they did nothing to make the needed

corrections in time to save her life.

Following her death, *The Northern Echo* reported that a staff member from Tees, Esk, and Wear Valley NHS Tweeted, “Mental illness can kill a person, just like a physical illness. Not everyone survives. It's devastating” (Scott, 2020). Again, this aligns with victim blaming. When we are challenged on something we have done or said, it is a common human instinct to tell ourselves and others that the victim is at fault - *our* behaviour didn't cause the harm. Harm was inevitable because they were already ill. Nothing we could have reasonably done could have prevented harm. Psychotherapist Stephen Grosz explains this as “an unconscious strategy that aims to keep us ignorant of feelings in ourselves that we're unable to tolerate. Typically, we want to see ourselves as good, and put those aspects of ourselves that we find shameful onto another person or group” (cited in Herman, 1994: 128). Distress doesn't just sporadically appear for *anyone*, regardless of what psychiatric label they have. People and situations cause distress, which means *they can stop causing it*. But it's so much more comfortable to simply think of the distressed person as 'ill' and destined to their fate of suffering rather than to face up to our own actions which cause harm.

The coroner conducting the inquest of Zoe's death found that: (1) information placed in her medical file should have first been discussed with Zoe; (2) information found to be factually inaccurate should have been completely removed; and (3) not doing this led to her taking her life and would likely lead to future deaths (Broadbridge, 2021)¹⁴.

Following the publication of the results of an inquest in June 2022, the Tees, Esk and Wear Valley Trust stated that 'lessons had been learnt', a common phrase uttered by institutions *after* they have been through the judicial process and found at fault. I find this phrase dishonest because it suggests they didn't already know the harm they were causing. In Zoe's case, she had been repeatedly clear about the distress they were causing. For services to use this stock phrase at times like this is insulting because it brings dishonesty into a statement meant to repair the trust they broke. It may be that such behaviours are done somewhat unconsciously at first, from a place of self-protection and inability to tolerate the discomfort of the hurtful acts perpetrated, rather than intentionally malicious act. Nevertheless, when awareness has

¹⁴ Zoe's Report can be downloaded at: www.judiciary.uk/prevention-of-future-death-reports/zoe-zaremba-prevention-of-future-deaths-report/

been raised and behaviours are not changed, what was once unintentional becomes wilful. This is when what might have started out as misinformation becomes disinformation.

HOW OUR EXPERIENCE HAS SHAPED MY RESEARCH

After the falsifications Dr Harris wrote about my son, I expected him to go out of his way to let others know he had made mistakes. As time went on with this not happening, I began to feel shame. I felt shame for not being able to protect my son, for not realizing I needed to be on guard from this doctor I had been idolizing, for not realizing that we lived in a world where my son and I were devalued because we have a psychiatric label. My ignorance left my son vulnerable.

I remembered the woman from the coffee morning. How unfair I had been to simply ignore her. Reframing my perspective was painful. I felt shame whenever I dared to tell others what I was starting to understand. I worried I would be told my thinking was flawed because I was autistic and greeted with hostility for suggesting that, as a middle-class white woman, I could be the recipient of oppression. Or simply laughed at. Or seen as egocentric for making something which involved my children about me. Learning to articulate my experience despite this was like learning to stand alone, chin up, while others surrounded me from all angles staring in disdain.

The humiliation was so painful I started seeking any way out of it. In the years to come, I took many risks I wouldn't have previously, which included taking up smoking and fighting a lengthy court battle knowing it could destroy my finances and my marriage and ruin my life in general. When exhausted from it all, like my son had, I also thought of taking my life. In my mind, I called it 'leaving'. If it ever got too bad, I could just 'leave'. Taiwo Afuape, author of *Power, Resistance and Liberation in Therapy with Survivors of Trauma: To Have Our Hearts Broken* (2011), reframed suicide as a way out of oppression - an 'act of resistance' rather than a sign of brokenness. That resonated with me. It's a 'fuck you!' to the people who think they can control you - in my case, to show the doctors and courts that their power over me had limits. I was able to fight harder because I realized when there was nothing more I could do, I could always choose to 'leave'.

Oddly, at what was likely the lowest point in my life, I applied for a place in the PhD program

at Edinburgh University. I applied because it had been the plan to do so before all of this started and doing this gave me something to hold onto, to keep me from 'leaving'. It was perhaps my frantic attempt to avoid total self-abandonment. But I only had enough energy for one application. I took the attitude that this was all I had in me, so if it was meant to be, then it would happen. I applied and was offered a place in their programme. My PhD studies and court claim were in opposition for some time—one making me feel I was important and capable of doing something worthwhile - the other making me feel completely worthless.

For some time, I actively avoided positioning my research question too near to my own experience as it brought up pain for me, and I could not imagine coping with that for the next four years. It was halfway through the first year of my PhD - when things were at their worst - when I read the humiliating investigation report Tracy Blackburn wrote, and I realized there was no way to avoid the triggers. As Michael Rosen (1989) says: You can't go under it. You can't go over it. You have to go through it.

This research has offered me a way of repairing the maddening incongruence Dr Harris and Ms. Blackburn brought to our lives. Through this research I have sought to understand why the actions of professionals have the impact they do. I believe this means understanding the importance professionals have in our personal lives. Putting the word 'professional' in front of a person's name, a relationship, or a behaviour does not stop human feelings of attachment and ruptured attachment, trust and hurt. I share the details of my experience openly because the pain and timing of it heavily influenced my research. The problem with my original research question: 'How can therapists support autistic clients to better cope with the experience of being misunderstood by a non-autistic majority?' is that it placed the emphasis on helping autistic people tolerate being misunderstood rather than demanding accountability from institutions that do not acknowledge their bias and the harm it causes.

My experience and my research have caused me to consider the issue of privilege and power in ways I never have before. I had been aware of discrimination based on a perception of class, accents, skin colour, religion, sexual orientation, and other protected characteristics. But it was not until examining the complexity of the discrimination my son and I experienced that I really started to understand how discrimination is embedded in our systems of society - unquestioned and maintained by self-protecting discourses and ideological power.

SUMMARY

Something I don't think I understood until just now - as I'm writing this - is why this event led me to so much existential reflection. I think I get it now. These events changed the meaning of my life. Before - the meaning of my life was to try to live happily ever after with my husband and children. To write and get a PhD and maybe move to France and grow cantaloupe and avocados. Then, in one fell swoop, I had two directions I could head - and both suggested suffering. I had to choose a path not based on finding happiness but based on which response I could most live with.

I could not cope with keeping everything neatly compartmentalized. There was no truth in that. My experiences inform my thinking. Trying to stay detached would have *also* informed my research. I decided it was better to be honest and open about how my experiences influenced my PhD direction. If it were not for the complexity and devastation this experience brought to our lives, this theme would probably not have become the focus of my research. It all started because I grew to realize that someone I respected and trusted did not see us as people I loved in the same the way we saw him - as a person. This study was born not only out of anger but also out of a desire to change the institutions which broke my heart and trust.

CHAPTER 5: 'OUR THOUGHTS ARE WITH THE FAMILY'

As the mother to two children with autism I learned early on that when professionals wanted something my husband or I felt wasn't in the best interests of our children, there would be low-level suggestions that we were not appropriate parents. When professionals suggest that the choices the caregiver is making potentially harms the child, it allows the institution more legal scope to put pressure on the family in order to ration the care. This is called having a 'legitimate aim' which allows them to disregard the basic human right to ['enjoy family relationships without interference from government'](#) (Known as Article 8 of the Human Rights Act, 1998). Conversely, the sanctity of a family's privacy is dismissed as irrelevant to a child's wellbeing and development by the very professionals who profess to be interested in protecting the child's wellbeing (Uher, 2022).

INVOLVING THE FAMILY

Many autistic people grow up to live independently, and I know some who are not close to their biological family. There can be a resentment when research seeks to look more at the experience of the family rather than the autistic person themselves. My goal with this research was to always privilege the autistic voice, rather than the professional or the family. For that reason, this chapter almost wasn't written.

In previous chapters, I looked at how ethnocentric judgments around autism permitted certain behaviours to be enacted against my son and myself. In this chapter, I will start looking at how those treatments affected my research participants over time as they developed a deep fear of being wrong, often leading to difficulty inserting boundaries, trusting others, maintaining connection to the world around them and living in a state of hyper or hypo arousal. But before I move onto their stories, I want to take a moment and look at how mistreatment can be directed towards the parents or carers rather than the child – thus creating the narrative that the parent is bad rather than the child. Whilst this *potentially* eases *some* blame from the child, it still has the effect of shifting responsibility away from the institution and continues to justify mistreatment of the autistic person.

To not include this chapter would leave silent one of the most insidious forms of control institutions can have on autistic people - which is to seek control through their private lives. In this chapter I explore how ethnocentric judgments around autistic people and carers permit certain behaviours to be enacted on the family, and how that then affects the wellbeing of the autistic person.

THE UGLY DUCKLING

From the start of my research, I found that I kept being pulled towards the classic children's story *The Ugly Duckling* by Hans Christian Anderson. *The Ugly Duckling* (1888) is a fable about a displaced swan growing up in a paddling of ducks. The swan is badly judged for not looking or behaving like a duck. There are many metaphors in this story which correlate with themes raised in this research. These include: (1) Ethnocentric judgments made about the swan when he is expected to look and act like a duck; (2) How those in power create the discourses that govern all the farm animals; (3) The scrutinizing of behaviour through 'the gaze'; and (4) The effects on the swan which included shame, feeling not good enough, becoming 'other-referencing' (a term I use to describe looking to others for confirmation of what is right), and suicidality. But what I was most surprised to see captured by this allegory was the breakdown of the relationship between the mother and her son; and the impact this breakdown had on her son - whose sense of okayness came from a parent who based their sense of okayness on institutional messages:

'Come with me now, I will take you into grand society, and introduce you to the farmyard. You must bow your heads prettily to that Old Duck yonder; she is the highest born of them all'.

The Old Duck stared, and said, 'Look, here comes another brood, and what a queer looking object one of them is; I wish his mother could improve him a little'.

'That is impossible, your grace,' replied the mother; 'he is not pretty; but I think he will grow up strong, and able to take care of himself. You must look at him the right way'.

But the poor duckling, who had crept out of his shell last of all, and looked so ugly, was bitten and pushed and made fun of, by all the poultry. So, it went on from day to day till it got worse and worse, and his mother said she wished he had never been born. Eventually Mother Duck left the Ugly Duckling who grew up without her.

In his adulthood he finally sees a bevy of swans. 'I will fly away to them, to the royal birds, and they will beat me, because I, that am so ugly, dare to come near them. Better to be killed by them than to be pursued by ducks, and beaten by fowls, and pushed about by the girl who takes care of the poultry yard, and to suffer hunger in winter!' (Anderson, 1888).

Self-blame doesn't always happen strictly on an individual level, it can be transmitted through the family or developed when one turns to their family for validation and protection only to find the family echoing the institution's messages of conformity. Parents or other family members take in messages about right and wrong ways of being, and then pass that on to their children. *The Ugly Duckling* is an example of Foucault's (1982) broader theoretical perspective on power and discourse, which emphasizes the ways in which social norms and identities are constructed and maintained through discourse and power relations. Anderson (1888) describes Mother Duck's awareness about how those in power would look at her son. She even challenges the observer that they need to *look at him 'the right way'*; but ultimately, she transitions from challenging the assessment of those in power to giving instructions to her children on 'the way of the world'.

The story of *The Ugly Duckling* reinforces binary oppositions between normal-abnormal and acceptable-unacceptable. Because such discourses have been fully internalized by Mother Duck throughout her life, she eventually succumbs to the discourses *over* her intuition as a mother. For a while she works anxiously to reinforce social norms and expectations. But finally, after pages covering the mother's evolution from anxiety to exhaustion, Mother Duck expresses the dark wish that her 'Ugly Duck' hadn't been born. I suspect this doesn't come from a lack of love for her child, but rather it was a question of which pain would be more bearable. The pain of societal injustice versus the pain of not having had her son.

In January 2023, I read a post on Facebook. It was a public post that had over a million views about a woman called Lucy Dunn, the mother to a child with complex needs. The author wrote:

Lucy was dealt a cruel hand - not by having her delightful son but by the system she entered when she had him. It is true that having a child with additional needs comes with additional challenges, but that is nothing compared with the challenges that come with 'the system'...I often find myself describing this system as abusive and I find a lot of the trauma that these parents go through is not because their child has additional needs but because the system makes it impossible...They have to sum up and waste their energy day after day, that energy could be better spent directly with their child, ... Lucy, like so many of the parents I work with was brave, and fierce and exhausted. Yet everyday she fought on until it became too much...Lucy is gone. She took her own life just before Christmas and society should hang its head in shame (Jones, January 12, 2023).

A NEW TYPE OF CLIENT

In the years since the acts of coercion and blame against my son and myself, I started getting therapy referrals for parents who had suffered similar experiences of coercion. The descriptions of the professionals involved were often cumulative and detailed. There were different dynamics and personality types being described but many stories I've heard contain elements of:

- A minority of professionals policing families with overt hostility from the beginning, seeming to have a 'nip it in the bud' attitude. The idea being that if parents understand there isn't a compassionate professional to work with then they will think twice about asking for extras for themselves or their child. As Waltz comments, "parent-blaming is never far away, because parental labour is the cheapest remedy and because it is so deeply ingrained in culture" (2020: 36).
- The majority of professionals were *not* operating strategically. They meant well. They simply didn't have the lived experience that the child or parent had and as such seemed to have a hard time conceiving that some children struggled in traditional education

settings more than others, or that the institution could be getting it wrong, and/or that neurodivergent families might present in a different way than they had been taught the ideal 'healthy' family was meant to look.

- Many professionals simply had a desire to just get through the day with the resources available. In other words, the system wasn't really set up to support neurodivergent children and professionals are in a position of 'having to make do'.

In the stories I heard there was a mix of explanations for how the professionals acted. Lisa Lightner, a U.S. special education advocate writes about this on her website "Welcome to a Day in Our Shoes" when she says, "Sometimes I do believe it's ignorance. But sometimes, I can't help but think that it's deliberate and that they are trying to convince us to go along with 'their way' even though they know it's wrong" (October 2015). Regardless of the reason for the difficulty the results were always harmful for the parents and child.

Another factor that I suspect was at play was a sense of pressure the professionals felt to not miss a safeguarding concern. In December 2021 at a debate covering the death of Arthur Labinjo-Hughes, Secretary of State for Education, Nadhim Zahawi stated that, "if there is any evidence, any inkling, any iota of harm to any child, *that the child is taken away immediately*". Despite this strong statement, five months later Zahawi admitted that his wife would occasionally 'smack' their young daughter (Forrest, 2022). Putting aside the debate on physical acts of discipline, for me this raises the question who gets to decide what constitutes 'harm'? - especially if authorities have stated that children should be removed when there is even a hint of it. As a parent I find such directives scary, but can imagine that professionals also must find this scary because when a child dies from abuse, the professionals who knew the child or their family are often named and written about in the news as having failed in their duty to protect the child. This is more than just having failed at 'a job' this is a moral failing - a personal punishment to the professional.

It is my opinion that safeguarding concerns are often raised by professionals who have a deep fear of missing potential harm, and it isn't helpful if they happen to have a lack of understanding about neurodivergence and/or they may have been offended by the child or parents involved. Instinctively, as parents, we do know that if we want a professional to push

back against the remit of the dehumanizing institutions in which they work we need for them to like us on a personal level. This dynamic is the power imbalance which can lead us to responses such as fight, flight, or fawning. In other words, we present as scared, angry - and in-between we try to be charming. This comes across as dysregulated emotions. I have heard of instances where teachers and social workers have given Mums an amateur diagnosis of 'emotional instability disorder' - which is another term for borderline personality disorder. Parents have been ordered to have therapy for an anxiety that wasn't present before professionals got involved with their lives. The message seems to be that having an emotional reaction to the involvement of professionals is irrational and must be a disorder.

The stories my clients brought all had different details, but their responses to what they had been through was the same. Lost sleep, crying, loss of joy in their life, fear of the phone ringing or any interaction with professionals, feelings of extreme anger, a sense of attachment to the professional relationships and feelings of shame about the attachment. And an overall sense that others wouldn't understand the complexities or intensity of their feelings.

John Gottman is a prominent psychologist and relationship researcher known for his work in the field of marriage and couples therapy. Gottman (2006) coined the term 'meta-emotions' to describe how individuals and couples think and feel about their emotions. Meta-emotions are essentially emotions about emotions. Gottman and colleagues propose that the concept of meta-emotion encompasses more than just an individual's emotional responses to their own emotions. It also includes how individuals regulate and manage their emotions, as well as how they perceive and respond to others' emotions. According to Gottman (2006), there are two main types of meta-emotions: 'emotion dismissing' and 'emotion coaching'. Couples who engage in emotion dismissing tend to invalidate or ignore their partner's emotions. They might belittle or criticize their partner for feeling a certain way or tell them that their feelings are unwarranted. This can lead to feelings of shame and dysregulation. I would propose that this doesn't only come up between intimate partners, but with individuals who have a sense of feeling invalidated in general. For many of my clients the simple fact they were experiencing distress at their mistreatment evoked feelings of shame. It occurs to me that this is another internalized bias in which the individual has become self-policing. And there are often gentle nudges from the professionals to suggest that 'mum's anxiety or upset' is 'disproportionate or making matters worse' which then reactivates the parent's insecurity about their response.

Many parents didn't feel they could confide in those close to them about their experiences of being accused of irrationality by professionals. They feared not being believed, validated, or understood by those listening. One parent compared the idea of telling their friends what was being said about them by the professionals to telling someone they were accused of being a paedophile. They hadn't been accused of that - but the feeling was 'It is simply so bad that you don't say anything. Nice people aren't accused of things like that'. Another client said that 'most people just won't believe there isn't smoke without fire. People think professionals are there to help, so if you're saying they have accused you of something there must be a reason'.

A documentary on Netflix, *Take Care of Maya* (Roosevelt, 2023) tells of the Kowalski family's experience when Beata (mom) was accused of deliberately making her daughter Maya sick. Maya was taken from the family's custody. After an extended period of wrong accusations and hostility, Beata eventually ended her own life. Following Beata's death, two of the doctors involved in her daughter's care had the following text exchange.

Doctor #1

'Learned today that ketamine girl's

mom committed suicide yesterday.

Sorry to say my prediction was correct.'

Doctor #2

'OMG... this is terrible.

I know we did the right

thing, but this is really

f***up. I feel bad.'

Doctor #1

I had another mother do this same thing.

We definitely did the right thing for the child.'

In this exchange I hear the objectification of the child whom they simply refer to as 'Ketamine girl', a disdain for her mother (just a day after her passing), and a lack of regard for a second mother they referred to who 'did the same thing'. There are also echoes of a narrative that they were seeking to protect the child. They 'did the right thing'. In other words, *not* the wrong thing - for which they could be held responsible. The doctors who exchanged these texts were not held responsible for Beata's death. They were not named. But had the child died because they had failed to act, they would have been. My point is that there is less of a consequence to professionals when *their* actions harm the child than when they miss the harm someone else might cause. The discourse that they - as professionals were right and the accused mother was wrong - protected them from guilt and from having to push back against a harmful institution. Getting accusations of child abuse wrong, while it still harms the child, *to the point of people dying*, carries less of a consequence for the professionals.

Many of my clients spoke about wanting to simply leave. Walk away from the family or, as the word had meant for me, die. None of them did, but they were sharing a sense of desperation that there was no other way out from this life of institutional abuse. And along with everything else, they all felt responsible and flawed for the extreme stress they were failing to manage better. One client tells me she googled, 'Can you die from stress?'

Ethically I was torn between taking these clients. Their stories were so close to home for me, and at a time when I was struggling to process my own trauma, I had to consider if I could really sit and hear them and see them without projecting my own experience onto them. On the other hand, I *knew* I understood their pain in a way others wouldn't. I didn't have the answers for coming out the other side, but I could sit *with* these clients, look them in the eye and tell them they were *not* crazy. I could tell them their responses were responses to trauma, and that their experiences were shared amongst other parents who had gone through the same thing. I found that when someone is suffering from something many people don't talk about

openly, the thing that is most soothing is to hear you are not alone. This is why the phrase, ‘Me too’ resonated with so many people around the world. To help communicate this shared experience I started to make a list of common themes the parents spoke about. This list is comprised only of general themes and no specific client data.

In making this list I quickly started to notice parallels between the themes these parents were sharing and the experiences I heard from victims of domestic abuse. Below is a chart with themes from ‘Special Education Needs and Disabilities’ (SEND) parents I sat with in the left column and the features of coercive control as defined by the Crown Prosecution Service in the right column.¹⁵

Table 3. Institutional Coercive Control v Personal Coercive Control	
THEMES RECORDED FROM CLIENT WORK	CPS EXAMPLES OF COERCIVE CONTROL
Fear that their relationships with needed professionals would break down and that this would impact their child’s ability to go to school, get support and the parent’s ability to work.	An ongoing dependency on the perpetrator for support of basic needs to include the needs of one’s children / place of education or ability to work.
Being told that all other professionals share the same point of view, so that the parent had little hope of finding something different from someone else, should they be dissatisfied with one professional.	Being told that no one would believe them / validate their perspective.
Having one’s parenting choices called into question.	Encouraging self-doubt or blame to prevent disclosure to the authorities.

¹⁵ www.cps.gov.uk/legal-guidance/controlling-or-coercive-behaviour-intimate-or-family-relationship

A fear they will be seen as irrational if they complain. Often the irrational mum or the SEND parent is labelled pathetic or being bitter about their lot in life.	Creating shaming conditions in which the victim doesn't feel able to talk about their experiences with others.
A fear that the complaint process will be deeply humiliating and further the already experienced trauma, with little hope of achieving justice or the correct support.	Threat of personal humiliation with little hope of escape.
Parents felt mentally exhausted trying to determine whether speaking up or staying silent was better for their child.	Controlling someone's basic needs or their children's needs to the point of exhaustion.

Interestingly the themes also seemed to present in similar orders: Stage One - gratitude for the relationship. The wonderful doctor, teacher etc; Stage Two - a growing awareness of problems with the relationship, whilst questioning their own perspective. Am I overreacting? Am I the problem? They say it's me; Stage Three - trying to figure out how to get one's own or one's child's needs met without upsetting the person or people they depend on; Stage Four - a growing anxiety about repercussions should the relationship breakdown; and Stage Five - feeling anxious, trapped helpless and exhausted.

Coercive control is a criminal offence under Section 76 of the Serious Crime Act 2015¹⁶ if these acts are committed by someone with whom the victim has a *personal* relationship. Despite this legal qualifier, the UK's Online Psychiatric Services Agency noted that coercive control is not just committed by romantic partners¹⁷. It can occur within professional relationships.

Stage Two – a growing awareness of problems and 'questioning their own perspective' was for many the most distressing as it caused parents to doubt themselves and to later wonder if they waited too long to act, or perhaps could have done more if they had had the confidence.

Examples of subtle discrepancies which might creep into the relationship include:

¹⁶ www.legislation.gov.uk/ukpga/2015/9/section/76/enacted

¹⁷ www.psychiatry-uk.com/coercive-control/

- How language is used: ‘Parent refused to accept support offered’.
- When details are extrapolated and presented without context: Not explaining why the parent disagreed with the offered support or felt it would not be helpful at this time.
- Small inaccuracies: Stating a child has a *mild* case of X when their diagnosis states that it is *severe*. This can mean the institution doesn’t need to supply as much support.
- Failing to give contexts: The child received a consequence because they were rude during class without explaining what behaviour caused the perceived rudeness or what precipitated their behaviour. Extrapolating even clearly stated facts from the surrounding context builds a misleading picture of the person as unpredictable, when in fact they may have been having a very predictable response to something which caused distress.
- Including irrelevant pieces of information: ‘Mum is not British and doesn’t have friends in this country.’ This example was from paperwork written about myself in which the writer was suggesting I was a flight risk because I had no friends in the UK. Although this was beside the point, it was also untrue.

Over time, as the parent remained compliant and grateful to the professional, there was an erosion of the parent’s power to protect their child. This awareness sunk in only when there was a big problem and all the little ways in which the parent and child had been misrepresented were now a solid picture with a history and paper trail portraying the child as ‘at risk’ and the parent as a ‘safeguarding concern’. This was a feature of every story coming from a client who sought therapy around institutional abuse. Tania Tirraoro, founder and co-director of the website “Special Needs Jungle” interviewed education Lawyer, Nathan Davies and quotes him as saying:

Parents struggling to cope and requiring additional support in the family home, are often deterred by the threat of intense scrutiny and criticism by social services. The possibility of raising child protection issues or launching even care proceedings (in extreme cases) are tools local authorities are increasingly using, especially during these times of austerity and public

sector cuts. But cuts can in no way be an excuse for such unnecessarily heavy-handed approaches being employed (August 31, 2017)

Many parents feel that trying to protect their children or challenge the 'support' provided by the institutions will be, "treated as evidence of parental awkwardness, or of the parent having something to hide" (Aiello, 2021:7). An independent review of children's social care (chaired by Josh MacAlister) interviewed "care-experienced parents who describe the undignified position of being subject to child protection investigations if they seek help, which in turn *stops them asking for the support they need*" emphasis added) and that "the system appears to be disproportionately spent on assessing and investigating families instead of providing support" (2021: 30). Even in cases where the only reason for involvement with children's social care was due to the social care needs of an autistic child, there was a tendency to evaluate the parenting capacity of caregivers through a child protection lens rather than focusing on the social care needs of the child. This approach can be problematic as it may not adequately address the unique needs of autistic children and their families and may instead "perpetuate negative stereotypes and misunderstandings about autism" (2021: 7). The report goes on to note that the net effect of this disparate treatment is that many families find themselves at a mental, emotional, physical, sleep deprived and financial breaking point, with the knock-on effect to the autistic individual's 'development, educational attainment and adjustment to and increase the risk of poor health, additional impairment and social exclusion (2017: 6-8).

Between my client's stories and the overstretched lawyers, I reached out to, who seemed to be handling claims far bigger and more shocking than mine, I was quickly coming to understand that what we had experienced was commonplace. Good parents are made to sound awful: Inappropriate, damaged, trying to get our own emotional needs met to the detriment of the child, we are labelled as overly anxious, narcissistic, neurotic, and a massive safeguarding concern in general. Sadly, what was also common was the misguided feeling these parents had, that I had had, which was that what happened to us was rare. Or that on some level *they* had done something wrong, that *they* were damaged, or *their child* was particularly complex. Basically, something about them or their family was responsible for the abuse they received. This fear kept them from pushing back and left their children vulnerable with inadequate parental protection against the actions of the institutions.

I heard so many stories where the parent speaking to me felt scared to speak up. If the drama was over, social services had finally left their lives, or the child finally received a place in a different school, the parent would simply try to move on with a sense that there was no recourse to the injustice. They clearly had lingering trauma but felt complaining would only make it worse. And, as the therapist, interested in their mental well-being, I couldn't disagree. It was like sitting with an abuse victim scared of complaining and agreeing that, *yes*, it might actually be worse to speak up. I am not alone in this ethical conflict. In the movie, *Take Care of Maya*, we see the Kowalski family lawyer - Debra M. Salisbury's advise Beata that, "The best way to get this case to end successfully, in my experience, is to convince everybody that you have changed your mind and that you're going to do what they tell you to do..." (even though Beata never did anything wrong)... "And when you get your child back never ever go back" (Roosevelt, 2023). The lawyer understood what I understand - the truth does not matter. At the end of the day, the institution *can* take the child away from the parents. The only thing that matters to most parents is whether they want to risk that by standing up for their right to privacy and respect. Very few parents fight for their rights because it risks hurting their child. This is institutional abuse.

It seems clear to me that the institution's main source of power is in making families feel insecure and afraid of being shamed or the removal of their children. But we don't call these acts 'coercive control' when this is done by professionals. This is another example of a contradictory discourse in which narratives are shaped to give power to one side over the other. Dominant institutions, such as governments, schools, and media, can present a unified front, creating a discourse on that which should be understood as criminal behaviour, whilst simultaneously reframing the very same acts when committed by those working to serve the institutions.

I put out a request on social media for parents interested in being interviewed about such experiences. I had two responses. I'm not particularly popular (I currently have just over 2,000 followers) which might be one reason for the lack of engagement. The first person to respond backed out owing to fears about being found out by her local council. The second person took me by surprise. She was a public figure. It greatly surprised me that she was amongst this small group of people who follow me. As with all my research participants I have promised to keep her identity private. I will call her Jane (a pseudonym) and her daughter, Samantha (also a

pseudonym). Jane spoke to me about feeling gaslit by Samantha's primary school, the exhaustion she experienced from this and the knock-on effect this treatment of her had on Samantha. I share Jane's extract below.

'WE BELIEVE YOU MIGHT HAVE ANXIETY'

The doctor rang me 'I'm ringing you because I want to check you're alright?'

school have contacted us and told us that you've been very anxious at meetings.

We believe you might have anxiety.

There was a lot of paperwork going back and forth.

I wasn't happy with what they've written.

I didn't think it reflected the meetings we were having.

If you correct everything you risk being seen as

'paranoid'

'anxious'

'Overly rigid'

especially if you have a diagnosis of any kind yourself.

or a 'difficult' parent

especially if this has already been said about you previously.

Your power to correct anything is really diminished.

BUT

if you don't speak up against small misrepresentations,

a picture about you and your children gets painted.

and dries as is.

You lose your power to fight back in the future if there should ever be a bigger problem.

You relinquish your power to protect your child in the future

in an effort to provide them support in the now.

It's scary.

You can only pray that your children don't get harmed in this system.

you are handing over your most precious thing

then they're saying you've got these vulnerabilities.

they're challenging.... Not even your interpretation of what you think they should do but...

your sanity.

They say that you're seeing things that aren't there.

I questioned everything I did.

Like, am I making this up?

You're just thinking that if you could just calm down a bit it would all be fine.

you're probably making it worse.

What's really cruel about it is that you're raising a child with autism you're already

questioning yourself and your capabilities as a parent.

There was so much valuable information from this interview that would be worth sharing. Above is only a small part of what was said. As an overview of Jane's story, what seemed to transpire was that Samantha's primary school was not fully honest with Jane about the methods staff deployed with Samantha, or Samantha's emotional response to these methods. The school also greatly discounted the legitimacy of Jane's concern about Samantha's needs as a young autistic girl. As Samantha came to the end of primary school, she started to exhibit extreme anxiety and developed an eating disorder. I make the argument that many issues such

as anxiety are not inherent with autism but result when a child suffers long term exposure to *overly* challenging environments.

Eventually Jane and Samantha had an illuminating conversation in which Samantha explained that she wouldn't eat when her mother wasn't around because she felt deeply unsafe, to the point of feeling physically ill. Samantha expressed resentment towards her mother and a sense of betrayal that she had not better protected her from the primary school environment. Samantha spoke to her mother about treatment from staff that Jane had previously not been aware of. Samantha - now in high school - is working to recover from these early life experiences and to feel safe in the world again which - many psychologists will agree - means trusting that your parents are able to provide a 'secure base'.

The secure base theory was primarily introduced and elaborated upon by John Bowlby in a series of influential books and articles. One of the key publications where Bowlby presented his ideas on attachment theory and the concept of a secure base is his seminal book titled *Attachment and Loss*. This three-volume series, published between 1969 and 1980, includes "Attachment" (1969, "Separation: Anxiety and Anger" (1973), and "Loss: Sadness and Depression" (1981). These books outline Bowlby's research, theoretical framework, and empirical evidence supporting his ideas.

In addition to his books, Bowlby also published several articles and papers discussing attachment theory, secure base, and related concepts. Some notable articles include "The Nature of the Child's Tie to His Mother" (1958), "Processes of Mourning" (1961), and "Attachment and Loss: Retrospect and Prospect" (1979). These works contribute to our understanding of the secure base theory and its implications for child development and relationships, with the main thesis to emerge being: The child needs to feel attached to and protected by their parent. To disrupt this attachment and relationship is likely to result in an insecure attachment style for the child as they grow. And yet, when institutions apply scrutiny and stress to the parent, they are almost always disrupting this secure base.

OVERSTATING / UNDERSTATING

Autistic people get judged, but so do the parents. Jane was judged as overreacting. Those judgments about Jane together with judgments made about Samantha led to Samantha not

having her needs met in school and developing anxiety and distrust of others. This judgment combination of parent and child was: The parent is neurotic (overly anxious or protective), and the child is taking on mum's anxiety when she 'shuts down' at school. This is an example of a self-protecting discourse which places blame with mum rather than school and leaves the child at the mercy of the professional's judgment, and the parent unable to effectively protect or support their child.

The above is a common judgment of parent and child. Below I list other common judgments I have heard from different parents and teachers:

JUDGMENTS ABOUT THE PARENT

- The parent is overly anxious about the child's needs- the institution doesn't need to provide the adjustments being asked for.
- The parent is overly optimistic about the child's abilities- the institution doesn't need to provide the support being asked for.
- The parent is a bad parent, their parenting needs to change, the child would most benefit from being made to follow same rules as everyone else. If the child is distressed by the school's methods this suffering can be explained as a byproduct of the home environment which didn't prepare the child for the institution's expectations.

This is the case with 'Oliver McGowan', an 18-year-old, who had mild autism and learning difficulties, who was given olanzapine to sedate him, despite his parents telling medical staff not to give him the drug. He died in intensive care 17 days later after a rare side effect caused his brain to swell¹⁸.

Another young man, age 22, Mark Stuart died in hospital as his parents were repeatedly ignored when Mark was experiencing dehydration and was in pain and needed prompt medical attention. His parents were required to be with him at all times to help him communicate. For most of the time Mark was in the hospital his parents were trying to reassure Mark that the staff were helping, and he would be better soon. Like many other parents, Mark's father, Richard, spoke of regretting that he didn't fight harder against the institution that was letting

¹⁸ <https://www.bbc.co.uk/news/uk-england-bristol-55157372>

his son down, stating, "I feel so guilty that I didn't raise the roof."¹⁹

In all of these instances the differences in perspective are explained as 'parental bias'. The parent's perception is flawed because the parent is biased, often due to inappropriate emotional attachment to the child. We do not speak honestly about 'professional bias' which may be dictated by a need to restrict resources, tick boxes for governing agencies that hold the professional to account for matters like attendance and academic performance. Or the professional's desire to not be reprimanded or shamed for missing a safeguarding concern. *But we don't talk about professional bias.*

As an effect of ideological power, the accepted truth is that parents have bias and professionals don't. The fact that consequences to professionals are often very personal including shame and disgrace, the possible loss of their job with a knock-on effect to their homelife and family's well-being is not discussed. Following acceptance of the discourse, people trust that professionals don't hold personal bias, whilst parents can have certain other judgments applied to them. As Jane recounted earlier, "The doctor rang me, 'I'm ringing you because I want to check you're alright? School have contacted us and told us that you've been very anxious at meetings. We believe you might have anxiety'".

FIBS!²⁰

The accusation of the parent being overly anxious can quickly evolve into a clinical term 'Fabricated Induced Illness' (FII) or 'Munchausen by Proxy'. These terms are meant to describe a person who fabricates an illness about another person, primarily focussed on the *mother* fabricating illnesses about her child. FII was a term coined by British paediatrician Roy Meadows in 1977. Meadows is infamous for falsely accusing mothers of murdering their babies. Several of Meadow's victims were sentenced to jail time before having their convictions overturned (Wikipedia, 2023). Today, Meadow's successor, Danya Glaser continues on his work of training professionals to spot mothers who may be fabricating illnesses about their child. Accusations of FII disproportionately affect the families of neurodivergent children due to the subjective nature of neurodivergence and the difficulty of having an objective test for any psychiatric

¹⁹https://www.bbc.co.uk/news/extra/PD0zqQlsDt/our_sons_final_days_Mark_Stuart#:~:text=Mark%20Stuart%20spent%20five%20days%20in%20agony%20and,of%20the%20jetty%20and%20say%2C%20'I'm%20sorry%20Mark.'

²⁰ The term FIBS! Will be explained further in this section.

condition, but also due to how professionals are being told to identify FII.

I went to hear Glaser speak in London at a Child Safeguarding Conference on March 16th, 2023. According to Glaser, signs that the mother may have FII are: (1) she presented as anxious; (2) she seemed *desperate* to be listened to by the professional; and (3) she sought validation of her concerns about her child that other professionals claimed not to see. The claim that these were all warning signs of FII implies that mothers should never present as anxious about their concerns, seek to be listened to or have opinions that the professional doesn't agree with. This description reminds me of Freud's study of 'hysteria,' a term which was predominately given to women with a history of abuse. The term evolved from explaining emotional dysregulation as a response to abuse, to saying the women had fantasied the abuse all together, in an effort to receive pity and attention from the professional (Herman, 1994). 'Hysteria' has been largely discredited and the term is no longer used- although many would argue that the discrimination against women expressing emotions of anxiety or distress still exists and gets pathologized under different names. Borderline Personality Disorder is one example. FII might be another.

If we consider that anxiety can be a common response to pressurized situations created by institutions and possibly years of not being listened to or of watching one's child's needs be missed in the school environment, then it is easy to imagine that parents may come across as anxious and desperate to be heard. Unfortunately, desperation is seen as a sign of irrationality and can be taken to discredit the person's perspective (Afuape 2011; Johnstone & Boyle, 2018). It seems clear that if the parent's concern is discredited then there is less need for health or educational industries to make adjustments or use extra resources for individuals who deviate from the assembly line.

Following her introduction to the conference, Glaser went on to state that only "a *minority* of children are going to be *really* harmed" and that "most parents are *not* a threat to their children". That seemed a fair enough statement. She then recommended not disclosing suspicions of FII to the parent who seems almost certain to harm their child because the goal is to protect the child in that instance. This is a legal grey area, but never mind... What I found more concerning was Glaser's advice regarding the *majority* of parents whom the professional might *just have questions about* with no real basis for safeguarding concerns. When talking about *that* group Glaser tells social workers and doctors how to get around consent laws which

require the professional to ask the parent for consent to discuss their child with other professionals. To subvert this law and the family's right to privacy, Glaser gives the following advice:

'You tell the parent you can't understand what's going on.

You need to get some information about the child's health.

The principle is that we don't carry on.

We do an MOT on the child.

And we do an MOT *now!*

We *explain* that we're going to do this.

We're *going* to talk to other professionals.

We don't ask them for consent.

Because this is to do with a child's health.' (That's not how the law works in the UK)

'If the school says, 'Have the parents given you permission to talk to me?'

You say, 'Well, I've told them I am going to do this.' (Time stamp 24:00 on audio recording.)

To summarize my understanding of these instructions, it seems there are two steps professionals are being advised to follow:

Step 1: Don't give the parent an indication they have a choice. Many won't know their legal rights. The professionals can use that to their advantage.

Step 2: Then, let other professionals you seek to collect information from believe you have gained consent.

I find the fact that Glaser includes this second step to indicate that she *knows* there are laws around gaining consent. She anticipates being asked if consent has been given and is ready to

side-step this question if it comes up. The fact that she knows this means these are calculated instructions about how to get around human rights laws by deceiving parents and other professionals.

What I found most jaw dropping is that she is giving this as part of formal training on safeguarding and no one else in the room seemed shocked - aside from my lawyer (now friend, if she doesn't hate me for making a scene after the talk), who had invited me to this event. It reminded me of when Dr Harris wanted to first make the referral to the forensic team. He said, it was *his* decision to make, and this is what he was *going* to do. When I told him I had the legal right to withhold consent he seemed dumbfounded. At the time I thought he was just an arrogant man who had never bothered to pay attention to his training. Now, I realize, this might have been his training!

Glaser continued by stating that if parents wouldn't readily agree to this information-sharing it should be viewed as a 'red flag'. This reminds me of the feeling I raised in Chapter Four where I noted that, "any objection I might raise [to social workers] would be seen as confirmation that abuse was going on – the rationale being that if nothing untoward had happened in our home I should be happy to stand aside and let my family be poked and prodded just to be safe. In her talk, Glaser did not address the distress of families who were intruded upon or seem to consider how professional interventions would emotionally harm children. Ironically, Glaser's position was that if the parent had fabricated the child's illness and this led to the child being poked and prodded by professionals then *that* is harmful to the child. But - if the pokes and prods were introduced by the professionals - that would not cause the same harm. She even referred to the process as doing an MOT, a term in the UK which stands for 'Ministry of Transport' and is used to refer to the annual diagnostic assessment done on a car to show that it is still roadworthy. But Glaser was talking about children and was speaking about it as a matter-of-fact part of the professional's job to manage the care of children. I would argue that this use of terminology has the effect of dehumanizing the person the professional is meant to serve, and this mentality in childcare is alarmingly commonplace. Mitzi Waltz describes how this mentality comes about:

Child development is routinely measured against charts and schedules, and surveillance now begins even before birth, with ultrasound imaging of the

foetus and genetic testing.... current vogue for standardised parenting might as well come with an explicit analogy to Ford's assembly line. To use just one example: 'Triple P takes the guesswork out of parenting!' trumpets the website for an approach that bills itself as 'evidence-based' and 'for every parent' ... 'shown to work across cultures, socio-economic groups and in many different family structures' (Triple P International, 2019)....And while Triple P and similar parenting programmes can be chosen voluntarily, many families are ordered to attend by social service agencies or courts, with specific goals set that they and their child must achieve to avoid more harsh directives (Waltz, 2020: 36).

I looked around the room as Glaser spoke. The other professionals were nodding along. Some maybe just out of politeness. Maybe some were on auto pilot as it was just before lunch. But that in itself is scary. If there are a few people propagating this discourse that professionals are entitled to coerce and intrude upon the family as if they are objects to be examined, and others are too polite or zoned out to challenge it, then as a parent I would absolutely withhold consent for multiple agencies to empower each other as they intruded in our lives. When thinking about the exchange between the doctors who were discussing Beata Kowalski's suicide, I find that very often this comradery can turn into an echo chamber which ignores professional bias whilst alleviating any guilt and soothing self-questioning judgments. Speaking from my experience as a professional, this is something colleagues do for each other. I might express a fear that I got something wrong with a client and a colleague might feel a desire to reassure me: 'it's okay', 'it wasn't your fault', 'it wasn't that bad', 'the client was difficult', 'you're only human'. Of course, these statements hold some truth, but there is a frantic race to alleviate the painful reflection for those we work alongside because we like them, or at the very least often feel a sense of professional loyalty. The conference that Glaser spoke at that day had an overriding theme of professionals supporting other professionals. Essentially the message was one of becoming a unified front. But what does that mean when there is a culture of scrutiny and entitlement? Giving a group of people who don't respect your rights, or your personhood, permission to form a team in which they intervene in your life as a united force doesn't feel safe.

After her talk I approached Glaser and told her I found her instructions on how to bi-pass

consent 'dishonest.' I then said,

'They *absolutely* need to ask for consent.'

My son's doctor didn't know this.

It's shocking.

And she responded:

In English law there is no such thing as 'parental rights'.

There is parental responsibility.

There is no 'parental rights.'

'Yes, there is.

They're called *human* rights.'

'Well, I'm not talking about parents.'

'I'm talking about children.'

Actually, she was the only one in this exchange who mentioned parents. I mentioned 'families' and by changing the language from 'families' to 'parents' she was creating the discourse that the wellbeing of the child is separate from the wellbeing of the parent. By using the term 'families' I was clear they were interconnected.

Even though Glaser made 'parents' a separate thing - parents are important. Seeking to be quiet about the parents' rights as humans is an attempt to act like our wellbeing doesn't matter. When parents are coerced, they can feel deep anxiety and experience a breakdown in trust of all professionals. Also, the child gets missed and goes unsupported because professionals aren't listening to the person who knows the child best. When professionals ignore the importance of the parent, they are creating an environment where the professionals are overly confident and unaware of their arrogance or ignorance. Following this conversation, I

took to calling FII, 'Fabricated Induced Illness Bullshit' (Fibs! - for short) – and will use this term in the remainder of this thesis.

On a slight aside, a psychologist named Fiona Gullon-Scott was due to speak at the same conference. Gullon-Scott specializes in diagnosing autistic females and fighting against the misuse of Fibs! amongst neurodivergent families. Prior to the conference Glaser said she wouldn't speak if Gullon-Scott was also presenting. A friend at the conference informed me that the organizers cancelled Gullon-Scott in order to keep Glaser. Should this be true, and I can imagine things like this happening easily, this meant the professionals in the room only heard one side of this issue and were denied an opportunity to hear challenging discourses and then weigh them up for themselves. This is how power can work to create that which can be known and that which is kept silenced. I am mindful of the paediatricians and social workers leaving that conference with only the information Glaser gave them - and the families this will impact.

THE NEED TO BE NEEDED

Whilst professionals are increasingly talking about Fibs! as a condition which might be exhibited by parents, what is not spoken about, but has much the same profile, is the 'saviour complex' which refers to a psychological phenomenon where an individual has an exaggerated or inflated sense of responsibility to rescue others. They may seek out careers where they can play the role of a rescuer or saviour, and they may even unconsciously create or exaggerate problems to fulfil their desire to rescue an imagined victim.

Autistic blogger, Kassiane Sibley wrote an article entitled, "The helper personality scares me..." In this article Sibley (2013) points out that the helper often bases their self-identity on the idea that they are helping. She then goes on to explain that to base one's whole sense of self on this concept becomes quite scary for the recipient of the 'help', because the helper will then struggle to tolerate any potential criticism of their method. If being a helper is one's sense of self, then having one's style of help criticized feels too personal. And when this is the case, there is no room for the professional helper to actually *be* professional.

I too am a professional, and by nature most of us seek helping roles *because* we want to give someone a better experience than the one we had. *We want to rescue*. In the same way I wrote about my need to be mindful that I might project onto the parents who were coming to me for

therapy, all people risk projecting their experience onto others. Professionals simply need to be mindful that this is a risk which can cause harm to those they want to help. The conversation about fabricating a problem shouldn't be seen as something only parents might do. We use terms like parental bias, but not professional bias. 'Fil' but not 'saviour complex'. We need to acknowledge that both have bias and a need to feel needed.

LEAVING

My clients talk about their exhaustion, and detachment and the thoughts of leaving one way or another. It is not the child they are longing to escape. It is the institution. But the child will suffer from the loss of a parent. And children suffer from watching their parent's marriages fall apart. And they suffer from the obvious stress and anxiety that the parents carry. How parents are judged and treated absolutely affects the child. Pretending that it doesn't only protects the institutions who use high pressure tactics to influence the parents. I do not mean to absolve parents of their responsibility to be brave in the face of oppression. But the obligation of the parent to be strong should not be taken as license for professionals to coerce and mistreat us. It is exhausting; and it *squashes the joy out of the family*. In most cases the parent stays connected to their child, but other relationships suffer. Marriages break up. Families fall apart in other ways. Familial relationships (between siblings, parent and children, and spouses) are all potential casualties of the stress and trauma caused by institutional coercion. To not acknowledge the extreme influence institutions can have on autistic people by proxy, is to choose ignorance: *Of course, this affects the child*.

SUMMARY

It is important to recognize the very real implications that arise when a parent's voice is dismissed. This has a direct and lasting impact on the quality of support and care that the child receives within the institutions of medical, educational or social care; but also, this impact extends even further, permeating through their home and most trusted relationships. The sanctity of the home, which should ideally serve as a refuge from the external challenges posed by institutional judgments, becomes compromised.

CHAPTER 6: 'LESSONS HAVE BEEN LEARNED'

They will label your suffering and illness.

They will call it depression,

while you call it a natural effect of oppression.

They will feed you pills to cure social ills.

Medicate injustice.

They will name the imbalance of power in society

a chemical imbalance in your brain.

They will refuse to understand the causes of your pain.

They offer terms like anxiety disorder

and post-traumatic stress disorder,

and you wonder what this apparently ordered way of living is. (Sanah Hasan, June 30, 2020)

PERMISSION TO COERCE

I read an email the doctor had sent to school before making a referral for my son. He wrote, 'Mum doesn't want this. We have to be gentle but firm.' The tone was calmly paternalistic and entitled. I found reading those two sentences to literally trigger my gag reflex. Of all the things he had said and done these were not going to be seen as the most important by anyone. Raging about them would only make me seem ridiculous. I hated the way these words made me feel so I tried to forget them.

I would later hear these same words repeated by Dr Danya Glaser during her talk on *Fibs!*, "When making a referral we must be gentle but firm". People in the room nodded in agreement: as professionals we must be 'gentle but firm.' As if their efforts to inject some

performative gentleness into their acts of coercion made them benevolent. As if any outrage at this disregard to our right to autonomy made us dysregulated when they were being so calm whilst violating our rights. They thought they were good people.

"The White Man's Burden" (1899), a poem written by British poet Rudyard Kipling, portrays colonialism as a noble mission, suggesting that the burden of uplifting and civilizing the 'lesser' races is a moral obligation. Once the judge accepts that their observations are correct there is then permission for certain acts to be committed against the individual, often reframing punitive restraints into more 'positive' controls whilst they see themselves as benevolent forces. This type of dynamic has a structure in which the dominant group appoints themselves with a legal or ethical responsibility for the 'protection' of the disempowered group and are seen as martyrs to serving and sympathy for their compassionate acts. The term 'white man's burden' has since become a catchphrase and symbol of the paternalistic and often oppressive attitude of colonial powers towards the indigenous populations they sought to dominate and control.

BACK TO THE BEGINNING

The birth of the asylum allowed for a more medicalized form of discipline to be deployed on those with differences. In this evolution a major consistency was the act of objectification, looking upon someone as an object to be scrutinized and judged, rather than related to.

Foucault (1979) makes the comparison between institutions such as schools and prisons in that they both require the subjects to have a production value in keeping with the industrial revolution. People, including children, were starting to be viewed and treated like cogs on a wheel within a machine. Correct functioning was dependent on the cog on the bigger wheel having the power to turn the smaller cog on the smaller wheel. We can think of the large cogs as professionals and small cogs as service users. The family is often made into a cog too. Research conducted by Matos and Pinto-Gouveia (2017) has demonstrated that chronic objectification, which Foucault writes about, leads to the same observed behavioural responses as physical-threat traumas. These include hyper arousal, fear and avoidance, aggression, extreme states of distress, *disassociation* from self or others, and emotional numbing (Corrigan, 1999, Falk, 2001).

Today, acts of segregation might be more nuanced in that neurologically deviant people are placed in separate units at school, again sending a devaluing message of Otherness. Ultimately a person's value is often based on how well they support the infrastructure. I have heard such rationale echoed by teachers and doctors when discussing a child's needs for reasonable adjustments. The argument is that either the child is so disabled they must be placed in an alternative provision, or they must mostly conform to the mainstream setting with minimal adjustments. The child is expected to 'grow up' and manage in 'the real world' (as if that is a fixed thing) so they need to get used to noise, crowds, long school days, pressure to perform, power, hierarchy, and assholes- because 'this is the way of the world' – as Mother Duck realises (Anderson, 1888). There is an expectation this is what the typical working environment has in store for children in adulthood so they must figure out how to manage it when they're young.

In the later years of the twentieth century, the idea of normalization was promoted by some disability theorists and researchers as a means of individual and social emancipation, as well as a sign of personal and social progress. The normalization principle was popularized by Wolf Wolfensberger (1983), who founded a social movement that sought to integrate people with cognitive impairments into the wider community by enhancing their self-perceptions, their ability to advocate for themselves and by transforming their appearances to make them more socially acceptable. However, the underlying assumption of these normalization strategies is that there is a right way to live and be. This assumption has been linked to Foucault's (1982) concept of biopower, which highlights the productive nature of modern power in producing objects and inducing effects rather than solely being repressive.

A CONVERSATION ABOUT TRAUMA AS AN INEVITABLE PART OF LIFE

May 2023:

The other night I had some friends over for dinner. One was a retired mental health nurse and the other a psychotherapist. When they asked about my research, we quickly got onto the topic of the way children are treated at school. One friend spoke of having her hands swatted at school when she was only five. After hearing the details of this I said, 'That's abuse. That will have been traumatizing.' She nodded and confirmed that it had been. My other friend then made the point that trauma is simply part of the human experience. I nodded. I agreed with this statement. She then referred to early Greek mythologies which spoke of people

experiencing great grief when they lost a loved one. I said that I agree that we would all experience trauma in our lives, but the abuse my first friend spoke of was a choice someone made, whereas the loss of a loved one was an inevitable part of life not chosen. Even if a relationship ends through choice, it is often not done purposefully to incite suffering. Whereas punishment is created for just that reason. Someone is manufacturing a painful situation to change our behaviour to fit their idea of good or correct behaviour. So, while yes, trauma is a part of everyone's life, some types of trauma are preventable. I believe those types to be *more* damaging because the recipient will be aware the act was manufactured by another to cause them pain. These traumas cause a sense of shame and break down our ability to trust others.

I would suggest *behaviour* focussed modalities were born out of a desire to modify people whose behaviours didn't fit societal moulds. But I also believe there is hostility under the surface for many professionals seeking to modify deviant behaviours. I imagine this might be a controversial statement, but I will support my belief with examples of the times when hostility reared its head. The reason I want to identify the hostility behind the acts is because there is a tendency for institutions and professionals to claim ignorance rather than intent, then when the behaviour is said to be changed, it is often simply renamed to sound different than what it was. For example, a common expression of social rejection of difference is simply silent disengagement - despite the deep impact ignoring someone can have on their self-esteem (Cain, 2017). It may be tempting to think that such treatment is not something that would be used in a professional setting, however, the reality is, the same behaviours are reframed as 'treatments' of autism. Applied Behavioural Analysis has formalized this form of rejection so that it can be used in the classroom environment. It is called 'Planned' or 'Positive Ignoring'. The term 'planned ignoring' originates from an older practice called the 'silent treatment' which was a form of discipline used in the prison system until the prison reform act of 1835 (Butler, 2016). Although seemingly done away with officially within prison systems, this technique seems identical to 'planned ignoring' now deployed in education systems. Advocators for the technique state that it deprives the 'disruptor' of a 'platform' and reinforces the 'respect' for existing power dynamics within the classroom (Booth, 2017). Whilst this may be easier for the professional in the short term, this technique has been criticized as having a poor long-term effect on the child. Studies have shown that this treatment leads to low self-esteem (Rittenour, 2019), and rejection sensitivity; and, because it does not allow for the development of conflict resolution skills, it often teaches aggression in order to

get needs met (Cain, 2017).

Rita Jordan, a professor in Autism at the University of Birmingham, published an article on the British Psychological Society's website about the 'double empathy' problem in care. Jordan (2019) wrote that she frequently sees 'positive ignoring' used in response to autistic behaviours. In line with the above findings regarding the 'silent treatment', Jordan finds that one of the effects such treatments have on students is that they learn to 'exhibit extreme behaviour to achieve their goals and, over time, these behaviours become their default mode, especially in situations where they feel trapped' (Jordan, July 4 2019).

Below I share a sign commonly used in schools when ignoring a student. Another response I can imagine might be for the student to simply disengage with others and to live in their own reality - which might offer more consistency than trying to live in the world around them. Templates such as the one below can be downloaded for free from the internet.



Figure 5 Stop, ABA

Beyond the fact that the hostile act of ignoring has been reframed as an official intervention to address unwanted behaviour, this has been reinforced with the universally recognized STOP sign. Everything about this symbol reminds us of an authority we are accustomed to complying with. An authority which is part of our daily life. Perhaps it is visualized as being part of the neighbourhood in which we live. We respect this sign because it keeps ourselves and others safe. But here it is not being used for the purpose of safety as with my stop light analogy in Chapter Four. When using well-known indicators of authority, people are often attempting to exercise ideological power in which others are expected to acquiesce without question.

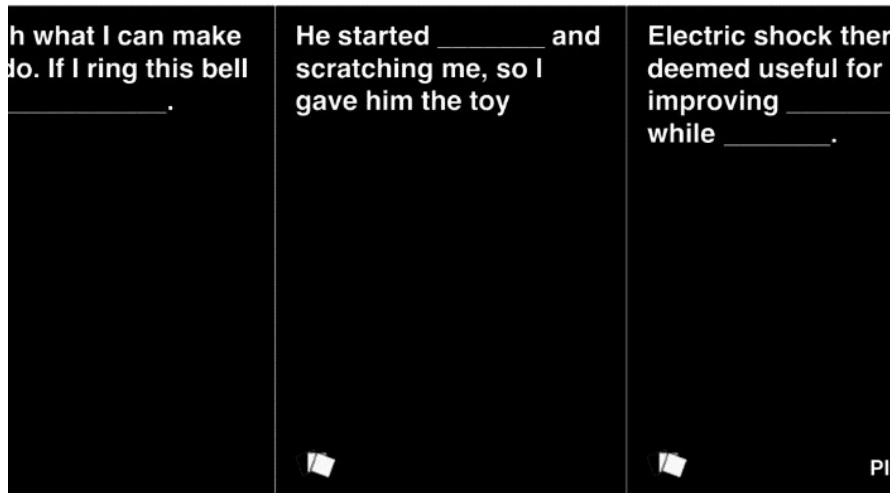
I would also point out that: (1) The sign labels the child's behaviour as 'attention seeking'. This is a blatant example of the teacher ascribing an identity to the child; (2) Using ideological power, there is an implied understanding that seeking attention is wrong. There is no room for considering why attention was sought. It is simply the normalized truth which we should all automatically agree with. Seeking attention *is* wrong; (3) By posting a sign that can be read by anyone using an audience to create the effect of shame means the student isn't just being silently Othered. It is a sign to let everyone walking by know about it; and (4) This 'treatment' also reenforces the teacher's power in the class and acts as a deterrent to other children from having their needs for attention met.

Discipline is used to reenforce the strength of the institution, but this endeavour is prioritized above the wellbeing of the individual. As a result, as I argued in Chapter 3, more and more people are suffering from institution induced stress and more clinical labels are being created to accommodate for this need to 'name' the various types of deviations or failures to cope.

I previously made the claim that behind such treatments lies hostility. To evidence this I now look at how *sanctioned* abusive practices, classed as 'treatments' for autistics turned into a card game by a group of senior Applied Behavioural Analysis psychologists who created a bespoke version of a popular card game, Card's Against Humanity.

CARDS AGAINST HUMANITY IS A GAME WHOSE OWN CREATORS DESCRIBE IT AS, "A PARTY GAME FOR HORRIBLE PEOPLE."....UNFORTUNATELY, THE RESULT IS ANYTHING BUT FUN. IN FACT, IT MAKES LIGHT OF SEVERAL ABUSIVE PRACTICES THAT ARE NOT CURRENTLY RESTRICTED BY THE BEHAVIOR ANALYST CERTIFICATION BOARD, "PINCH THE NOSE TO RELEASE THE JAW" A TREATMENT USED DURING FEEDING THERAPY. OR HAVING AMMONIA SPRAYED IN YOUR MOUTH AS A PUNISHMENT FOR NONCOMPLIANCE. THE CARDS ALSO INCLUDED MULTIPLE REFERENCES TO PHYSICAL RESTRAINT, ELECTRIC SHOCKS, AND FECES.

BELOW is an image of the cards described above.



Following the public outcry one member of the organization defended the act saying that professionals needed to ‘blow off steam’ (Luterman, 2017). To some this statement may sound reasonable, a common-sense argument. It could go hand in hand with statements like ‘we are too sensitive’. But - if we were to take the above card game and replace it with a racially biased version of the game- the defence that it was just a way of blowing off steam would be less acceptable.

It's important to note that this incident was not an isolated case, as there have been other instances of dehumanizing behaviour. For instance, in *From Chaos to Calm*, Martha Gabler (2013) compared the training of autistic children to animal training and suggested using the clicker method, a popular technique for training dogs where a button is pressed to produce a pleasant sound to reward good behaviour.



Figure 6 A presentation on how to train humans.

To consider the extreme discrimination such training sanctions amongst professionals, one might take the word 'autism' and replace it with any other disempowered group. For example: 'TAGTEACH FOR GIRLS IS THE CONVERGENCE OF HUMAN TRAINING, ANIMAL TRAINING, AND THE TECHNOLOGY OF PROCESS'.

I will now move onto *unsanctioned* acts of hostility, such as the multiple hospital scandals which have come to light over the years. I wrote a poem from the dialogue heard in BBC's *Panorama* videos. The following are words that were spoken to or about people with autism:

Bad Stuff Happens

Why is it that mental health services get so much press

the service has caused a death

failed a person

Not everyone survives

Bad stuff happens

She's only crying

if she slit her throat

you'd know it

she'd tell everybody

about it.

We're sorry for the insensitive comments.

I love watching you lot jump

Go on do it

Why don't you jump out of somewhere you can fit out of

I'll hold the window open for you

When you hit the floor do you reckon you'll make a thud

or a splat?

C'mon I'll keep it open for you

We're sorry for the errors in judgment

fat cunt

a good fucking target

I would fucking rugby tackle

the cunt down

I pinched her skin

It's gonna leave a bit of a mark

I get away with murder here

It was an isolated incident

Let me know when you've got some balls

and we'll have a fight

Do you want me to get a cheese grater?

And grate your face off?

Get a razor and cut you up?

Lessons have been learned

If you have to smash her...

smash her

I'll just whack them all down

Because if somebody gets hurt

The first thing the manger ask you is

'Why wasn't she on the floor?'

Our thoughts are with the family

(BBC, 2012; BBC, 2019; BBC, 2019²¹)

Much of the abuse that happens is silenced and - on the rare occasion that misconduct towards autistics is highlighted and professionals held to account – it is then spoken about as if it is an isolated incident.

It is not.

Jayne Connery, director of the Care Campaign for the Vulnerable (CCFTV), has given her take on the case, claiming that the care sector needs to do more to learn from these incidents. She said:

The Panorama exposé this week confirming the culture of abuse at Edenfield Centre is best described as 'more of the same'. Clearly nothing has been learned from the Winterbourne scandal, or the Muckamore Abbey perpetual abuse culture, or the Whorlton Hall Hospital debacle, or the very many others over the years that have briefly entered our awareness then faded to

²¹ www.youtube.com/watch?v=5MOQbLLX95E&t=43s
www.youtube.com/watch?v=cuBbbCagKJI&t=105s
www.youtube.com/watch?v=KAUkzWFFdqQ&t=30s

become distant memories. (Emphasis added) 'This was a CQC-rated 'good' facility, yet clearly a culture of abuse has existed for a very long time' (Lewis, 2022)

Much treatment goes uncontested for a long time before it is acknowledged. Professionals then argue these abuses are *not* examples of professional treatment, I argue *this was a treatment from professionals* and it does not matter *to the recipient* whether such treatment was conducted in accordance with rules books the care recipient will never read. To the recipient - surrounded by a group of professionals either engaging in or ignoring the abuse - this behaviour has been sanctioned. Bias, in one form or another, has been sanctioned. *And when even official treatments mirror abuse, the message is it was sanctioned from the top.*

CONVERSION THERAPY

As shocking as the hospital scandals are, the abuse is not so different from early methods deployed by clinical psychologist and professor, Ole Ivar Lovaas. Albeit Lovaas may have had a less overt, more calmly paternalistic demeanour whilst administering such treatments, I find that the attitude behind them feels the same - *I am allowed to exercise my power as a professional to gain compliance from you.* In Life Magazine on 7th May 1965, the photo essay 'Screams, Slaps and Love' portrayed the lives of four children on the autism spectrum. The article focused on the treatment Lovaas was developing, which used rewards and punishment to change children's behaviour. The essay showed many photographs of the children being slapped and forced into the desired behaviours (Bowman, 2014).

A critical evaluation of the article pointed out that it was Lovaas' intention that punishments made up only 2% of the treatment, with 'positive reinforcement' making up the other 98% (Larsson, 2011). The term 'positive reinforcement' is deceptively, well, positive. To show what I mean, I have shared photos of the 'positive' reinforcements. Figure 6 depicts the positive reinforcement of two boys receiving sherbet as they practised the act of giving each other a hug.

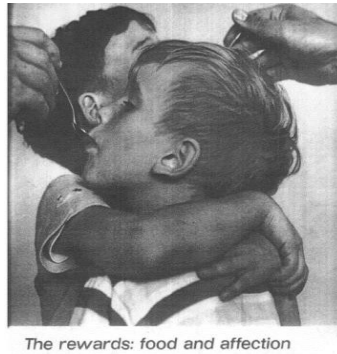


Figure Six: Reward for Affection

Although this is meant to depict a positive intervention, I find this picture gives me a somatic response of repulsion similar to the words I read in the doctor's email.

I believe that behaviour-based interventions *both* break down trust and - as a seeming contradiction - cause a person to seek the reassurance of the other. When we don't trust something or someone, we need to check on it *more* often. There becomes a constant need to understand the perspective and wants of the other. This is born out of a deep fear that we will be punished if we get it wrong. I call this being 'other-referencing' meaning that as the person grows older, they are looking to others to tell them what is right. Some autistic bloggers compare interventions meant to teach 'social skills' (or social norms) to autistic persons to 'conversion therapy'. As is noted on the Mind website:

Conversion therapy reinforces the feeling like there's something wrong with you, or always feeling like you're the odd one out in a room, or you're not living the way that everyone else is living and therefore certain aspects of society are denied to you or there are barriers in place (Mind, "Conversion 'Therapy' Ban").

Some professionals argue that behaviour focussed therapies can be damaging to an individual's self-esteem and identity and may lead to feelings of shame and inadequacy. Shame researcher, Francis Broucek asserts that, 'A pattern of noticing *things* about the child instead of paying attention to what the child feels is a pattern of shame-inducing objectification' (1991: 137). I

find that it is often the subtle and unnamed acts of Othering that cause the most *felt* sense of shame - like a sieve in which larger chunks don't quite make it through, the smaller bits keep flowing through at a steady unobstructed pace and are the acts which will eventually cause the damage. When harm is subtle - or delivered by someone considered an expert - it often does not get picked up or acknowledged as devaluing. It leads to the victim having an additional experience of pain in that it is invalidated.

When we are hurt by persons or circumstances in our life, and others take a position of neutrality, it feels as if our perception of reality is not agreed with by others, and our rights and innate value are not recognized. This is frequently referred to as invalidation trauma and leads us to struggle to feel secure in the world around us. This additional trauma of invalidation then compounds the original wounds. This will complicate the original trauma experience because our sense of fear is no longer limited to the incident which took place, but now extends to the wider world around us, causing unproven others to feel unsafe. I believe that people who have suffered invalidation trauma often take a position of hyper vigilance and start looking for early signs of rejection from others and struggle to make connections, express their needs or trust that others would be understanding or legitimizing. There is much research to suggest that prolonged experience of discrimination, harassment, and shame can lead to the onset of complex post-traumatic stress disorder (PTSD). Studies have shown that individuals with autism are at increased risk for anxiety and depression (Lever & Geurts, 2016). Minority stress may also contribute to a range of other mental health concerns, including low self-esteem, social anxiety, and post-traumatic stress disorder (Cai et al., 2019). Judith Herman (1994) tells us that people often state that they have suffered more due to the lack of validation and acknowledgment from others who were aware of what happened than they did from the original event. Boyle and Johnstone expand on this:

A child who has been abused by a neighbor and who has been able to confide in a parent who believed, supported and comforted them, assured them it was not their fault and took steps to protect them has a good chance of coming to terms with this traumatic event without lasting damage. If, on the other hand, they had no one to confide in, or they were disbelieved, or the abuser told them that they had invited the abuse and would be punished if they told anyone, then they are likely to take on meanings such as 'It was my

fault'; 'I am a bad little girl/boy'; 'I deserve to be punished' and 'People can't be trusted', which in turn give rise to feelings of shame, guilt and fear (2018: 108).

People who have experiences of invalidation from a young age may understandably hold little expectation of understanding or validation from others in their adulthood and hold little belief that they can protect or acquire justice when they are violated. I believe these impacts not just the inner psychological experience in the moment of violation, but the wider sense of safety in the world, which hinders one's ability to relax enough to build relational connections with others or insert boundaries in adulthood. Institutional experiences of Othering and invalidation like those who obey the 'position ignoring' signs seep into our personal lives.

The consensus that the treatment was 'okay' does not change the experience for the individual but instead offers them something to hang onto, such as the thought that it was really in their own best interest that they were treated that way. I think of children who have been the recipients of corporal punishment who tell others that their parents spank them because they love them because that is the narrative they were given.

As Dr Jean Mercer, the leader of the group 'Advocates for Children in Therapy', a not-for-profit organisation dedicated to ending harmful practices for treating children's mental health, points out, "We've all experienced aversive conditioning. We touch the stove while it's still hot, it hurts, then we become very cautious about touching it" (Delfin, 12 July 2018). Certainly, this is the idea behind behavioural psychology. Although Mercer goes on to make the point that when one person *manufactures a punishment*, it creates a breakdown in the recipient's sense of self-worth and their trust in others - similar to the experience my friend had at school when she spoke of having her hands swatted.

Treatments such as Lovaas' are not gone today. *The Guardian* reported on the Rotenberg Center in Massachusetts where autistic students were required to carry devices in their backpacks which delivered electric shocks when they 'misbehaved'. The Rotenberg Center's founder is Matthew Israel, who trained at Harvard under B. F. Skinner (Delfin, 2018). Another popular therapy which originated with ABA was 'holding therapy', where the autistic child was forcibly held until they 'surrendered' and made eye contact. This type of intervention was

developed by Niko Tinbergen (1983) in their animal behavioural research. This treatment is still used and proposed by professionals today. In an Infant-Parent Psychotherapy Training Program I attended in 2022, the speaker recommended forced eye contact as a way of ‘helping the autistic person’ to form better attachments. In my view this is perhaps the most closely linked to conversion therapy. As Julie Roberts writes on the website “Therapist Neurodiversity Collective”:

The true lesson of training social skills teaches our students that unless they learn to successfully mask their autistic traits, they are inherently less valuable members of the human race. Social skills training communicates conditional acceptance based on the conditions that non-autistic people determine. It’s not fair or ethical (February 15, 2020)

In, *Autism Spectrum Disorders: Interventions and Treatments for Children and Youth*, Richard Simpson (2005) argues that interventions such as holding therapy may have negative long-term effects for the child and later adult because this type of intervention may break the trust they had with their caregiver and teach the child that their desire for boundaries is not valued (Simpson, 2005). In a recent social media post, autistic blogger Kristy Forbes wrote that “compliance therapies take our autistic children’s NO and turns it into a Yes. This is grooming”²². Although to be fair ‘grooming’ was originally a benign term in which an individual or a caregiver was preparing the person for an event. The question to consider is when is this healthy and when is it harmful? To consider this we might look at what behaviours we are trying to change and why. We might also consider how our attempt at changing these behaviours changes the person and prohibits them from functioning in the world in other ways. Whilst preparing a child for ‘grand society’ are we depleting the child’s developing sense of self for personal boundaries? Getting someone to behave in a way that violates who they are programs them to rely on the perspective of others before recognizing or trusting their own instincts, a concept I have referred to earlier in this thesis as ‘other-referencing.’ Despite the disconnect from one’s own feelings, the person will still remain on high alert, rarely able to relax with others who may at any point reject or punish them.

²² www.facebook.com/intunepathways/posts/600449080564189

TRAUMA

Peter Levine defines trauma as “Anything we cannot cope with” (Garcia, 2020: 117). While most people think of trauma as coming from a ‘one-off’ event, much of the time trauma is a result of events which are ‘multiple, predictable and cumulative’ (Afuape, 2011; Herman, 1994). This is in line with my ‘sieve’ analogy in which I spoke of the steady flow of everyday micro-aggressions minority groups often face. Failures to include discrimination as a trauma inducing event for autistics may stem from a position of the privileged in which neurotypical researchers only see autistic persons through a narrow lens of dysfunctional traits all neatly explained by the diagnosis. If we consider that autistic persons are often being asked to function in environments which are counter to their needs, then one might argue that autistic people are far more likely to encounter experiences they cannot cope with.

It’s important to note that this is not the first time that traits of trauma have been relabelled as a psychiatric condition and proposed to belong to a disenfranchised group of people. The earliest descriptions of PTSD came under the heading of ‘hysteria’. This was thought to be a condition belonging primarily to women (Herman, 1994), many of whom had suffered badly from abuse and oppression. White male physicians classed this response to suffering as a disorder of the brain rather than society. The symptoms that made up hysteria were documented as screaming, weeping, freezing, mutism, unresponsiveness and extreme emotional dependence on others. These same symptoms would later be used to describe ‘shell shock’ in soldiers who came back from war (Novaes, 1947). Most of the therapy work I do with neurodivergent clients is around the effects of complex trauma because, as human beings, they were vulnerable to the hurt they have encountered by others because they work differently.

I find it interesting that Hoff (2015) notes that Bleuler recognized that schizophrenia not only had primary traits, but also secondary traits that were a response to societal mistreatments. Keeping in mind that in the late 1800s schizophrenia was described by the same traits that we understand as autism today, it would make sense to understand that Bleuler was recognising trauma responses of autistics.

In the same way that the traits of ‘hysteria’ could be reframed as ‘shell shock’ so can they be reframed as ‘autistic traits’. Sebring (2021) comments that hysteria and its legacies are an example of a broader issue where medicine works to regulate, discipline and control non-

normative bodies that are responding to the distress of discrimination. This relabelling continues to put the illness on the individual by denying the legitimacy of their response to a world in which they are oppressed. Unfortunately, when legitimate anger is expressed, those in positions of privilege can then find it easier to discount the rights of neuro-minorities citing that they are dysregulated and their thinking is flawed to start with. And then they story their upset as proof of their irrationality.

This is a very tidy self-protecting discourse. Below is a description taken from *Medical News Today*, explaining how Gaslighting effects the victim:

The victim may start to believe that they are imagining things, has some kind of mental illness, or has a faulty memory.... It is possible over time to get so beaten down and so sure you might be at fault, that you can't identify the dynamic. The Gaslight Effect happens over time – gradually... (Huizen, November 30, 2023)

'YOU'RE OVERREACTING'

I believe that the above is a form of 'gaslighting,' which is a common accompaniment to acts of discrimination. Members of the dominant group will often blame the victim for misunderstanding when they speak up about experiencing discrimination. It's important to understand that regardless of the intent or awareness, the harm done is the same. 'Gaslighting' not only leads to cognitive dissonance, low self-esteem and disempowerment on the part of the victim, but it can foster further dependence on the abuser as the only valid and veritable source of judgment, truth and memory.

There has been much research to suggest that autistic people have a diminished sense of self. In her online article "Memory and Sense of Self may Play more of a Role in Autism than we Thought", Lorna Goddard (2016) suggests that our sense of self decides how we will respond to 'problematic situations', which is in keeping with my own theory. However, while this may be part of the biological developmental delay that is autism, I suspect there may also be a social element that- over time- causes us to distrust our own perception and sense of self. And this *compounds* the difficulty with social communication and spontaneous responses.

TRAUMA RELABELLED

A study by Daniel Hoover (2018) focuses on the intersection of autism and childhood trauma.

Hoover concludes that children with ASD who experience an increased number of ACES are at a higher risk of experiencing co-morbid psychiatric and medical health problems. A gap left from this study is that it looked at the effects of negative social interactions between peers without considering the possibility that professionals often have more power and can also do damage.

Another concern I had when searching for literature was that anyone researching ‘trauma and autism’ might categorize trauma by a set list of events such as those noted by Mehtar of “witnessing or being a victim of accidents/disasters/violence sexual and/or physical abuse” (2011: 539). This would fail to include participants who have experienced something more in line with ‘minority stress’. Perhaps this is a good place to explain that what we consider ‘trauma’ can only be determined after the fact. We cannot say that a car accident will always be experienced as a trauma. We can only say it was traumatic if it was experienced as such - meaning the person felt traumatized. In other words, what is and isn’t a trauma depends on someone’s reaction to the event (Finlay, 2012).

Charles Myers, who examined some of the first cases of PTSD, attributed symptoms to the concussive effects of exploding shells and called the resulting nervous disorder “shell shock” (Herman, 1994). The name stuck, even though it soon became clear that the syndrome could be found in soldiers who had not been exposed to any physical trauma. Gradually, military psychiatrists were forced to acknowledge that the symptoms of shell shock were due to psychological trauma (Herman, 1994).

Studies show that autistic people are six times more likely to attempt suicide and seven times more likely to die by suicide compared to non-autistic individuals. With non-learning-disabled autistic women being thirteen times more likely to die by suicide. Negative childhood experiences, loneliness, social and communication difficulties, feeling like a burden, lack of support, camouflaging behaviours, and co-occurring mental health conditions are all factors that have been linked to an increased risk of suicide among autistic people. However, it is important to recognize that broader social, political, and cultural factors may also play a role in contributing to this crisis, such as exclusion from society and a lack of belonging (Rodgers, 2022).

The dismissal of minority experiences as ‘hysterical’ or ‘overly emotional’ has a long history of

being used to discredit and silence marginalized communities. This labelling is often used to delegitimize their experiences and emotions, particularly in situations where they are advocating for their rights or challenging dominant narratives. By portraying marginalized individuals as irrational or overly emotional, those in positions of power can dismiss their concerns and maintain the status quo. This type of gaslighting can be particularly damaging and isolating, as it can make individuals doubt their own experiences and feelings.

SUMMARY

Ethnocentrism often intersects with power dynamics where dominant groups hold more influence and control within institutions and society. This power imbalance can result in the imposition of ethnocentric judgments onto marginalized groups through policies, practices, and cultural norms, contributing to an environment where conversion therapy and institutional gaslighting can flourish. Institutional gaslighting refers to the systemic manipulation of facts, narratives, and realities to undermine the experiences and perspectives of marginalized groups. Ethnocentrism can contribute to this phenomenon by reinforcing the dominant culture's narrative as the 'correct' or 'normal' way of seeing the world and can result in the perception that alternative ways of being are 'wrong' or need to be changed. Many discourses around autism protect the dominant group from awareness of their bias. This can lead to institutions dismissing or denying the experiences of individuals from different cultures, thereby invalidating their lived realities and perpetuating harmful stereotypes. This can result in efforts to change or "convert" individuals to fit the dominant cultural norms, disregarding their authentic identities and causing significant harm to their mental and emotional well-being.

PART THREE: CASE STUDIES

CHAPTER 7: 'BECAUSE I SAY SO'

I'm only saying one thing.

When you treat children well, they're going to be OK

and if you don't treat them well, they're not going to be OK.

It's a very simple message

that anybody's great grandmother could have told them.

The fact that this message is even necessary

is a sign of the times.

(Gabor Maté, Sept, 2020²³)

INTRODUCTION

In previous sections I have offered the reader an overview of the clinical history of autism and shown how it has shaped a mainstream understanding of autism. This understanding affects not only people known to be autistic, but also those who are not known to be autistic, because it can mean that autistic traits which are not well known get missed and the individual is judged for ways of being that could be better understood looking through a neurodivergent lens.

²³ Quote taken from www.humanwindow.com.

In this section we meet my participants - Ziggy, Jen, Sarah and Bob - who share stories about their lives. Here, in this chapter they speak of a time when their autism is not yet known to themselves or the professional. Whilst we can't say the professionals were making a judgment about autism, I find these stories to be important for a few reasons: (1) many times in life, autism is not known by the observer (even when a diagnosis exists.) On many occasions the individual is judged by people who don't understand what reasons there may be for perceived differences; (2) Before autism was a diagnostic label, or before the scope of autism was broadened to include more people, it was the behaviours that were judged; and (3) *Even* when the person is diagnosed, the individual is often *still* judged through a non-autistic lens of normative bias.

THE PARTICIPANT'S STORIES OF HOW THEY WERE STORIED

Ziggy

As a participant, Ziggy stood out for me because he shared his stories in a more analytical way than the other participants, who spoke about their experiences in a more personal way. Having a mix of both styles worked well for the TIFDA (Trauma Informed Foucauldian Discourse Analysis) modality I use in my research, as it requires a look at both: (i) the power dynamics offered from an analytical distance; and (ii) the interpersonal effects on the individual. In this first lyrical transcription, Ziggy gives an overview of his impression of professionals he knew growing up. I chose to open with this as he does a good job of setting the scene for the other stories by reminding the reader that institutions are authoritarian environments in which the adult always holds the power (a foundational point in this chapter), and the child must conform in order to survive.

AUTHORITARIAN FIGURES

Their affirmation was:

they were right

I was wrong.

Nobody can really call them on anything.

*You think about Matilda,
making me feel that what I was saying was invalid.
That what they said was clearly more correct,
that's basically how I was treated
from the age of five
attending school,
by medical professionals,
teachers,
and everybody else along the way.*

Immediately, Ziggy is stating that 'they' (the professionals in his life) believed themselves to be right and 'I' (the child in their care) to be wrong. By saying 'Their affirmation was...' Ziggy qualifies this belief as belonging to *them*. He then highlights the absoluteness of their power, regardless of the reality of who was right and wrong, 'nobody could call them on anything'. The rule being that those in power created that which can be known to be true. Foucault's (1989) work highlights the idea of 'truth regimes' where certain discourses become dominant and dictate what is considered true or correct. Ziggy's statement 'nobody can really call them on anything' suggests there is a dominant discourse that is unquestionable, and it is likely reinforced by various authorities such as medical professionals and teachers. This aligns with Foucault's (1982) notion of how institutions shape and control knowledge.

I must confess that I haven't read *Matilda* a children's book by Roald Dahl; however, I have seen the films - and for me Ziggy's reference brings up images of the head mistress, 'Miss Trunchbull' who is constantly dressed in military attire, shouting orders at the children and the teachers. Ziggy's offering of this as a composite for his childhood experience is particularly fitting for a Foucauldian analysis. In *Discipline and Punish: The Birth of the Prison*, Foucault questions if it is surprising that "prisons resemble factories, schools, barracks, hospitals, which all resemble prisons" (1979: 228), meaning the ways in which modern institutions, developed

in the 18th and 19th century, have become interconnected to reflect a larger system of social control. According to Foucault (1979), the design and operation of these institutions all share certain features, such as strict hierarchical structures, the use of surveillance and disciplinary techniques to regulate behaviour, and the creation of normalized routines and procedures to control the behaviour of individuals. Further, in *Discipline and Punish*, Foucault (1979) claims that the modern understanding of 'normalization' originated in the 1700's in institutions known to house children and young people - such as orphanages or dormitories. Foucault goes on to discuss how strict routines and protocols were needed to keep those institutions running smoothly. To expand on this concept further in a series of lectures, Foucault (1978-79) explained that discipline was not simply used to prevent divergent acts, but to prompt acts which conform to the institution's needs.

Although Ziggy does not mention a need for emotional connection, he puts an emphasis on structure and conformity. The rigidity of the power structure means that 'from the age of five' children must compartmentalize their needs for relational attunement throughout the school day. There is a feeling of pointlessness in trying to challenge the authorized perspectives, which are decided by the adults. To apply the trauma-informed approach, I use the technique of empathic imagination, as I consider that Ziggy's reference to Matilda suggests that in his early life he might have had times of feeling objectified and experienced a lack of relational attunement. I imagine Ziggy, as a young child, surrounded by other young children: I believe he would have felt trapped in such an environment where none of his peers felt courageous enough to challenge the power structure. To feel missed, but also surrounded by others who do not have legitimized voices, strengthens the image of the power held by the authority.

In the same way that Foucault (1979) makes links between different social institutions, Ziggy goes on to generalize all adult-child interactions in his life - alluding to the multiagency approach, strongly suggesting he had a sense of 'total institutionalization' - where his existence was always marked by experiences of disempowerment and invalidation by professional adults. Despite his experience of oppression in such settings, Ziggy does not relinquish his own inner experience of life - but he acknowledges that those in positions of power were 'clearly *more* correct'. I'm interested in the word 'more' as it doesn't suggest there was a 'correct' and 'incorrect' but rather there was one perspective that was *more* robust than the other. This suggests *his* perspective still existed, even though he was made to feel 'invalid'. Another word

that comes to mind for me is silenced.

HOW WE STORY DIFFERENCE

The next two participants, Sarah and Bob, share stories about their early school experience. In these stories the autism is not yet known to the child or the adults in their lives. For this reason, we look at discourses around difference. This first set of interviews allowed for a better understanding of how professionals imposed institutional expectations onto the lives of the participants from a young age, thus *normalizing*, sometimes damaging, discourses about difference.

These institutions also create 'subject positions' that individuals are expected to occupy, in the same way someone might be a 'subject' to a royal court. A subject position is the role we are expected to play in society. In modern day, this role often involves being productive, efficient, and obedient to authority. Those who deviate from these positions are punished with derogatory subject positions such as the 'bad one' or the 'weirdo'.

When reading the text, a primary concern is to look at the impact those in power have had on the child's ability to find an acceptable subject position within their society. Both Sarah and Bob reported a sense of having their story retold by others without an understanding of their personal experience within the classroom environment.

Sarah

Like Ziggy, Sarah shares a story about how the teachers in her life had the absolute power to dictate that which is true of her. Her extracts demonstrate how discourses of blame can be internalized by the child. As Sarah tells her story it is clear through the emotion in her voice these accounts still hold much weight for her. We begin with Sarah telling the consequences of her being a mostly silent student in her class.

BEING INVISIBLE

Teachers would leave me to the side.

I could see how much attention other people would get.

I would just be left

to my own devices.

It was like being invisible

unless,

occasionally,

if I get told off

I think of a teacher who was screaming at me

because I wasn't doing my work.

My brother had died that weekend

I went into school as normal.

I'd not told anyone that he died.

It's not that I don't feel anything.

I struggle to process emotions sometimes.

and it didn't occur to me to tell anybody that he died.

Instead, I was sat there pen in my hand.

Instead of noticing how I was

she just shouted,

"You're such a stupid girl.

You're such a stupid girl,"

in front of the whole class,

I was humiliated.

I'd be distracted by everything around me,

then it would look like I just was not concentrating.

I was just daft,

I couldn't do the work.

Teachers would make comments like that

I had written an assignment

I'd got a really good mark.

One of the teachers came over to me and said,

"What did you have to do to get a good mark like that?

Because I know you didn't earn that.

I know something dodgy is going on."

There'd be assumptions like that

I think, because of, the way I came across in class,

because I was so, so quiet.

In maths, for example.

I'd do my homework

The answers would be right

and they'd say,

"Where's your working out?"

"I did it quickly in my head."

"How did you get to the answer?"

"Well, I thought of it and wrote it down"

They assumed I wasn't telling the truth.

I got detentions.

one teacher did support me.

She was my absolute favorite.

I still have contact with her now.

She was so passionate.

She was an English literature teacher.

She would say to me,

"I want to help you get to university.

Let me sit with you

and write this with you

because I want you to go on straight."

English was one of the subjects that I went to university to do,

If it weren't for her,

I don't know what I would've been doing.

She really did support me.

She was so lovely.

Sarah opens by explaining her inner experience as a child sitting in a classroom was to feel distracted by the *environment*, but it 'would then *look* like I was just not concentrating'. The word 'look' refers to the gaze of the teachers and the meaning they were making of her as a student. I emphasized the word 'environment' because this was what the teachers were not scrutinizing. The structure of the school, the rules and expectations went unchallenged when making judgments about Sarah.

Sarah says she felt 'invisible' suggesting that she went unseen and unheard by teachers. Of note is the fact that Sarah also did not tell the teachers things that one might expect - such as the fact that her brother had died. Sarah states, '*It's not that I don't feel anything. I struggle to process emotions sometimes. and it didn't occur to me to tell anybody that he died.*' This reminds me of the point I raised in Chapter Five using Bowlby's (1969) attachment theory to frame how communication can be impacted. When the child has an expectation of not being seen or heard, they may naturally become withdrawn and not expect to be seen and heard and thus stop making attempts to get their needs met. This lack of effort to be understood then leaves the other to make their own meaning of what is true. It should be noted that this is circular. Sarah may have been quiet because she was not properly understood, and she maybe misunderstood because she became quiet.

The observations made by the teachers was that Sarah was 'daft' and 'couldn't do the work'. This placed the burden and responsibility wholly with Sarah whilst offering immunity to the institution that may not have been offering Sarah what she needed to access education. I would suggest these statements relied on the discourse that some children simply don't live up to the expectations of the industry of standardized education. One of the benefits of this

discourse is that it allows the staff, the institution, and the government to reserve resources for only those who fit most easily into the mould, whilst blaming those who don't. As Sarah tells me this, I imagine her as a small child bewildered and overwhelmed by her environment, unable to name her experience while others decided what was true of her.

Bryony Shannon (2022) highlights how institutions use language to distract from their failings and maintain their power through their tendency to blame individuals for institutional failings - this then becomes woven into public service language. This can be referred to as 'ideological power'. Boyle & Johnstone (2018) describe ideological power as one of the most insidious forms of power because those who have it control not just what others are thinking - but also what they are supposed to *think about*. By weaving blame into our language there is already a lack of opportunity for the listener or observer to consider an alternative to the offered narrative. I will explore how language is used as a tool of ideological power later in the discussion section of this chapter.

With a sense of injustice, Sarah shared a time when she was accused of cheating, 'I had written an assignment. I'd got a really good mark.' Sarah's pride at having obtained a good mark was quickly taken away by the teacher's accusation she hadn't *earned* that mark. 'One of the teachers came over to me and said, 'What did you have to do is get a good mark like that? I know something dodgy is going on'. The term 'dodgy' is a Britishism which implies an act of dishonesty, but also it implies that one has the ability to be 'dodgy', cunning or in some way intelligent enough to be dishonest. This comment acknowledges Sarah's intellect while simultaneously refusing to consider that the institution or teachers may have made a mistake in their previous evaluations of Sarah's abilities i.e., going from an assessment of Sarah lacking intelligence to one of her possessing it but lacking good character.

'In maths, for example, I'd do my homework. The answers would be right, and they'd say, "Where's your working out?". "How did you get to the answer?"' Sarah is challenged repeatedly by the teachers who demand evidence of her working out - evidence of the importance of normalcy and conformity in the institution. She responds honestly to their questions, 'I did it quickly in my head. Well, I thought of it and wrote it down.' I consider that Sarah's understanding of her process, 'I did it quickly in my head' may have been the only way she could articulate the experience of symbiosis - which I wrote about in Chapter Three - whereby Sarah

is so immersed in the process of doing an equation she doesn't mentally break it down into steps and therefore finds it extremely difficult to show the working out as the teacher asks. Rather than get help to explore this way of processing information, there was an assumption from the teacher that if *she* couldn't understand this way of working, it must not have a legitimate explanation. Perhaps this implies that the questions the teacher asked were not really questions, but rhetorical, and the teacher had already drawn conclusions. Rather than explore this in more depth and try to help Sarah to meet the requirement of showing the working out process on paper, there is again an assumption that Sarah was lying. Again, this leaves the teacher in the position of being beyond question, with the burden of conforming to the institution resting solely on the child.

Sarah goes from being judged as 'daft' and 'dishonest' to being left to flounder without an accessible education even when there are clear signs of her intellect and opportunities for the teachers to engage with how Sarah's mind works. We could reasonably assume that for a young child it is deflating: (1) to struggle to meet the academic requirements of your school; (2) upon finally achieving a good mark - to be judged as dishonest for having managed to do so; and (3) or to have success ignored because it wasn't achieved in the 'correct' way and therefore was not counted as a legitimate success.

Bob

Next, I go to Bob's extract which illustrates the othering and objectification process he went through as a young child. In this extract Bob speaks with two different teachers. He uses 'She' in referring to the first one and 'He' when referring to the second. Although Bob's extract, and life, come to an optimistic conclusion, his emotional response in his earlier years might be the bleakest of all participants reminding us that not every child *does* survive the school environment.

MY IDENTITY

She grabbed me by the ear

and brought me up to the front of the class

she taught the class

with her back to me

Imagine

a person who's got problems trying to fit in

and teaching the class

with your back to them

She showed.

no compassion

no curiosity

nothing.

I saw myself as useless.

What's the point?

The only way I could fit in

were by being a troublemaker.

That could be my role.

That year

I hardly passed.

my projects were all late.

It was terrible.

In grade five, my life changed,

He said, "This is your chance to start fresh.

I want you to do well."

My marks went up to As.

from then on,

instead of the loser,

achieving well became my identity.

In the above passage Bob shares an early school experience of a teacher humiliating him in front of the class and then keeping him separate from the class *throughout the year*. In a part of the interview preceding this excerpt, Bob shared the reason he had been grabbed by the ear and separated from the class was that he was talking to the child next to him. He thought he had found a friend. But being put on display and then ignored left him with little chance for real connection as Bob was publicly Othered.

Foucault (2006) describes one function of authority is to organize bodies or behaviours into categories of normal and abnormal. He goes on to make the point that normal and abnormal are dependent on each other. One cannot exist without the other. The punishment of Othering cannot exist without the group from which one is Othered - meaning that the audience and thus the shame that comes with Othering are a crucial element to an effective punishment.

Bob's text reminds me of Foucault's (1979) understanding of modern punishment, which relies on the person's sense of self to be wounded in order for them to be transformed into docile bodies. Foucault's concept of 'docile bodies' explains how individuals, through various mechanisms of social pressure, come to internalize the perceived expectations of others, often

leading to self-regulation and self-policing of their own behaviour. Foucault (1979) introduced the concept of 'docile bodies' in his work on discipline and punishment. He argued that in modern societies, there are various institutions and practices (e.g., schools, factories, hospitals, prisons) that work to produce 'docile' or obedient bodies. These institutions employ techniques such as those discussed earlier in this chapter to discipline, control and mould individuals into compliant subjects.

The majority of students, who still form the class group are, by default, representing that which is normal. As Martin-Barlo notes "there is no learning without culture, ...neither can there be an I without We, ... a disorder that does not have a reference to moral and social norms" (1996: 46). This type of punishment relies on the person's ability to feel shame - which aligns with Bob's statement that he felt 'worthless'. This public display of power is called 'disciplinary power' as it establishes the teacher's authority amongst the group sending the message that he/she alone decides who is acceptable.

When we 'other', we are making the claim that the person is not of value in the same way we are. This is, at its core, how we dehumanize and objectify. Although Bob will have been on display to the classroom, the one person not acknowledging him was the one person with power to make a difference. Also, not only was Bob on display to the rest of the class, but the other children were also on display to Bob. He could see them together as a group receiving the attention he was denied. Creating a message that in contrast to him, they were *valued* and worthy.

Bob was left in this position for the entirety of the school year, leading to a child of 8 years old asking the haunting question: '*What's the point?*' I come back to this question further in the discussion as I point out that this question can lead to devastating outcomes for some children. In an act of survival Bob found a role he could fulfil so that his Othering was not absolute, 'The only way I could fit in were by being a troublemaker. That could be my role'. That year was 'terrible' having a negative impact on his grades, but moreover I would think it had a negative impact on his sense of self, as Bob had his identity assigned to him by someone else. Ascribed identities are the personal qualities and value assigned to a person based on the judgments of others. One of the earliest scholars to discuss 'ascribed identities' was the French sociologist Émile Durkheim in his book *The Division of Labour in Society* (1893). This concept shares some

commonality with Foucault's (1982) subject theory. Durkheim was concerned with the traits that might be judged such as race, gender and class, whereas Foucault's studies emphasized the role of power in creating such identities. In Foucault's view, individuals are not passive recipients of these identities but are actively engaged in negotiating and resisting them. Ascribed identities has been further developed by many other scholars, including W.E.B. Du Bois (1903), who explored the effects of race and racism on identity formation, as well as Erving Goffman (2009), who introduced the idea of "stigma" as a form of ascribed identity that can impact an individual's social interactions and opportunities.

The happy ending for Bob in this excerpt is that Bob did make it through this year and eventually met another teacher who offered him a different experience, one in which the adult remained emotionally available and willing to see Bob - not the reputation forced upon him - 'This is your chance to start fresh. I want you to do well'. At the time of our interview Bob was approaching 60, but the gratitude that he held for his grade five teacher was clearly still very present. The impact people (or anything) in power can have on us is significant. That is what it means to have power. If we have the power to help, then we have the power to hurt and vice versa. With this more benevolent deployment of power, Bob's grades rose to As and he learned that he could achieve academic success. This is a happy turn of events, and I am glad Bob had this experience. He has gone on to write books and become a wonderful advocate for the autistic community.

INTERNALIZED MESSAGES

Jen

I end with Jen who, like Ziggy, didn't share many specific experiences from her early education; instead I use a story she shared about a workplace experience she had as an adult. She is not speaking about clearly defined autism traits but instead about feeling unable to clarify her unspoken perspective. Jen's story is interesting because Jen herself was a social worker. Her story shows how misjudgments can also be made against professionals from other professionals. In the same way that autistic students may experience misjudgments and a lack of support from teachers, so might the autistic employee experience a lack of understanding and support from their employer.

Jen began working as a social worker for the local council in her mid-twenties. After years of working in the council Jen left her position to take a role at a private fostering agency with the expectation that she would be able to work more with families in the foster system. After Jen left her secure position with the council, she learned that her new role really meant she was expected to *market* fostering to people at the entrance of grocery stores.

Jen held a master's degree in social work and told me she would never have taken the role if she had known that was what they wanted her to do - 'If someone wants to foster children, they will already know that. They aren't going to suddenly decide to make this major life altering decision because you've approached them in a shop. And no one wants to talk about this in a grocery store in December'. Jen opens by describing her experience when facing her supervisor to report back on her progress of recruiting potential foster parents.

TENTERHOOKS

It was horrible

demeaning

demoralising.

I was constantly on tenterhooks

she would say, 'what progress have you made?'

I'm trying with what I have but you know...

she would look at me with a kind of perplexed look

they felt that I had lied to them about my capability of doing
the job

I was somehow the untruthful one
when it was really them
they hired me under false pretences
Like, this isn't what I signed up for.

I persevered
I tried my best.

a week and half after I got back from honeymoon
they decided to terminate my employment.

In Jen's case she was experiencing a loss of dignity and confidence in her role. Jen tells me that the job description never clearly explained what she would be doing. One might imagine that she would have felt upset with the employer, but I see her outward response as likely tied into an internalized oppression and a sense of not being entitled to voice her perspective. This goes beyond simple awareness of the other's possible thoughts becoming instead a perception that the other is somehow 'more correct'. The individual then feels afraid to voice any perspective which might challenge the other's account. Many self-silencing people may be scared to simply ask questions when confused for fear their question exposes their self-perceived abnormality - thinking, 'If the information isn't given that's because it's so obvious to anyone else who would already know'.

In the next half of the extract Jen evaluates the look she receives from her supervisor and understands that to mean she found her dishonest. Following this evaluation, Jen then clarifies that she knew she hadn't been dishonest and that it had actually been the employer who had misrepresented themselves and the role they were offering. This again ties into who has the power to create that which is true. But this had led to Jen making life changing decisions about her career. Nevertheless, Jen didn't raise this with her supervisor. Nor did these accusations of having 'lied to them' need to be voiced by her employer, they were already readily available in Jen's head - challenging her sense of entitlement to feel aggrieved or speak up for herself in the moment. Again, we see how communication can be circular. Eventually Jen was dismissed from her post. For Jen this sudden termination would be felt as a traumatic event that would haunt her for the next decade of her life. She never returned to social work or made further use of her master's degree.

DISCUSSION

Message: Differences are Immoral.

The participants spoke of times when their autism was not known, their way of presenting in school was judged as wrong and they were blamed for this. The discourse this suggests to me is that unexplained differences are immoral and the fault of the divergent person. From a Foucauldian standpoint, the stories my participants shared in this chapter look at how we judge the value of those who challenge the smooth running of the institution. As previously discussed, these differences are often framed as a failing of the individual. An example of such blame can be seen in an early name for ADHD which was 'Abnormal Defect of *Moral* Control' (Lange, 2010).

SUBJECTIFICATION

A major theme of the accounts shared in this chapter was the power dynamics between student and teacher. Ziggy brings this to life with his generalizations: 'they were clearly more correct' and 'nobody could call them on anything'. In the school settings, the teachers had the power to decide what was true of the students and these messages were conveyed to the student and others through words and behaviours. In some instances, the most powerful acts of communication were carried out in silence, in which the student was ignored. This can be

seen in Sarah and Bob's accounts of being ignored by their teachers. The teacher's indifference perpetuates the student's feelings of being useless and/or worth less than their peers. This illustrates how the teacher's actions contribute to the reproduction of power relations and shape the student's identity in a particular way. For me, this ties into attachment theory - which I have previously spoken about in Chapter Four. Inspired by Bowlby's attachment, Melanie Klein's 'object relations' theory argued that the development of self was hinged on our sense of security with others (Lapping, 2011).

Connections can also be made between Klein's (1952) ideas of self-development and Foucault's (1982) theories of subject position - especially in terms of understanding how individuals come to perceive themselves within larger social and cultural contexts. According to Klein (1952), the individual's self-concept and emotional well-being are influenced by their experiences in the early stages of life, particularly in relation to primary caregivers. If a person experiences a secure and nurturing environment they are more likely to develop a healthy self-concept, whereas adverse experiences can lead to emotional difficulties and insecurity. Foucault (2001), on the other hand, focuses on the role of institutions, ideologies, and societal norms in shaping individual subject positions. He argues that power, knowledge, and societal discourses are key in determining how individuals perceive themselves and their identities within a given society. It would seem that Klein focuses on personal relationships and Foucault does not. But I would argue that for young children, or for people who are in vulnerable positions in which they need to relinquish some measure of their autonomy, those who operate on behalf of the institutions become their primary caregivers and have the same level of emotional impact as Klein or Bowlby would anticipate.

Particularly for the young child, these institutional messages are felt as being transmitted through personal relationships. To illustrate this, it is quite common that a young child in school will absentmindedly refer to their teacher as 'mum' or 'dad'. Whilst it is likely an absent-minded mistake, it suggests that the child is relaxed enough to make this mistake. It would be an interesting research question to look at what year group this is reported to happen most and in which year it most sharply declines, and to then look at parallels in the curriculum or expectations of the child. Whilst we might argue that someone has 'let their guard down' - I would say this happens when the child is at an age where they don't have a guard to put up yet.

Klein's (1952) emphasis on early relationships and the development of a secure self-concept can influence how an individual perceives and interacts with external social structures, which is a key aspect of Foucault's (1982) work. A person with a secure self-concept may be more resilient and capable of resisting oppressive power structures and discourses, while someone with emotional difficulties stemming from early experiences may be more vulnerable to the effects of societal norms and power dynamics. In this sense, one's internal psychological development, as proposed by Klein (1952), can intersect with, and impact their external subject position within a Foucauldian (1982) framework. I find that these theories complement each other in understanding how individuals come to perceive themselves and their place within society.

In Bob and Sarah's stories, the teachers acted as both accuser and judge, effectively creating a story about who they were as people. This is represented in statements such as: 'they assumed I wasn't telling the truth. I got detentions'. The narrative created by the authorities isn't only centered on the work produced but it includes the character of the person. As Sarah says 'I'd be distracted by everything around me, then it would look like I just was not concentrating, I was just daft, I couldn't do the work. Teachers would make comments like that'. Sarah gives another example of this in the next passage when she describes being accused of cheating in math class. Sarah remains bewildered and affronted as she tells me this portion of her story, 'There'd be assumptions like that, I think, because of, the way I came across in class. Because I was so, so quiet'. To the outside observer, Sarah's inner experience was not understood. Instead, assumptions were made that she was *choosing* not to pay attention or that she was 'daft' a term that implies a lack of intellect. Sarah clarifies that teachers explicitly used this word to describe her. Sadly, I *can* imagine teachers saying such things in front of and to students and believe such offhanded comments to be commonplace having become normalized in professional cultures and they demonstrate an undercurrent of blame and hostility directed at the person who doesn't conform to the institutional standard, thus creating more work for the teacher. The awfulness for the person is that they simply must exist in the stories others create of them.

Most people are familiar with the saying, 'Knowledge *is* power'. But another well-known phrase: 'because I say so' suggests that some knowledge or 'discourses' are that which we are told and accept as fact because it comes from an authority figure. Ziggy expresses this in his

interview where he describes authority figures in his childhood, saying, 'what they said was clearly more correct' and 'no one could call them on anything'. In a Foucauldian sense he is discussing their power to dictate what is known or what is 'right'. But, because of the way he expresses this, it is clear that he is not saying he accepts their accounts. Foucault's (1989) theory on disciplinary practices highlights how institutions and authorities use various means to regulate and control individuals. For Bob, this is seen when the teacher grabbed him by the ear and separated him from the rest of the class. For Sarah, it is the act of being shouted at and given detentions for not doing her work. Beyond the injustice of admonishment, these acts are creating a narrative of Bob and Sarah as 'bad'. This creates knowledge which other children in the class, and likely Bob and Sarah to some degree, will have accepted as true.

Jen doesn't share stories from school, but we see how she might have internalized similar messages so that in her adulthood accusations don't even need to be verbalized, it is enough simply that a manager might give a 'perplexed look' and Jen starts to understand that she is being viewed as dishonest or lazy. Notably 'the look' becomes a common theme for all participants in future chapters. Jean-Paul Sartre, a prominent existentialist philosopher, introduced the concept of 'the look' in his work "Being and Nothingness". According to Sartre (1943/2020), this gaze has the power to make us feel objectified, seen as mere things rather than free, conscious subjects. In essence, 'the look' represents the way in which the gaze of others can influence our self-perception and create a sense of being observed and judged. Sartre delves into the existential implications of interpersonal relationships and the impact of the other's gaze on our sense of self and freedom. Foucault takes this idea and develops it further with his theory of the "medical gaze" (1989: 9) which more specifically highlights that such a gaze often comes from professionals.

In this instance, Jen was the Object being judged. Jen's internal critical ponderings reminded me of Sarah's experience in school where she was accused of being 'daft' in one moment and 'dishonest' in another. There wasn't really a permitted alternative to this perspective, as those in authority got to decide what is true. Although Jen didn't share many stories of professionals in her childhood, she assumed similar messages were being conveyed in the 'look'.

When being objectified, the options are to object or subject. Push back or accept. Whichever path we take, our outright rejection of the institution *or* inability to cope within the institution,

can be retold as either evidence of our badness or of a deficit belonging to us. We are storied in ways that place the responsibility with us because it alleviates the need for those in government (councils, education, social & medical care) to change. When public biases are seen as common-sense, overt acts of discrimination are seen as acceptable and also become common-sense behaviours which - in time - people feel okay about expressing openly – an example of which can be seen in Figure 7 below.



Figure 7: Overt Discrimination

A sign erected by white residents in 1942, Detroit. Source: Wikimedia Commons.

SUBJECTIFICATION / INTERNALIZING

In juxtaposition to the concept of the object is the concept of the subject. Whilst the object has things said about it or done to it, the subject has feelings about the things which are said, and they respond emotionally and behaviourally. *The object is perceived of by others. The subject perceives others.* Foucault was particularly interested in exploring the transition from Object to Subject as he states, “My *objective*, instead, has been to create a history of the different modes [of *objectification*] by which, in our culture, human beings are made *subjects*” (Foucault, 1982: 777). The transition occurs because the person who has been Objectified has awareness. They are not really objects, but people being judged and storied by others. The Objectified person then has a choice. They must decide how to act and be in the world so that

they can have the most comfortable life. For many this means being the good student or good citizen. Following the rules set by those in power, 'most comfortable' doesn't always mean comfortable. So, we make choices about what we can live with and what we can't. Sometimes we must challenge certain rules and discourses and suffer the consequences. We choose a position available to us and play our part. But subject positions have limits because others create the discourses that describe us. Although we can influence and challenge those discourses, it takes time and effort, and I believe having too many negative labels applied to us from a young age impinges on our ability to speak up and challenge the system.

For Foucault (1982) the subject is only part of the discourse, not creator of it. The effect these judgments have on our wellbeing can be explored by looking at how we respond to, and within, our subject positions. Foucault's (1982) concept of 'subject formation' involves how individuals are shaped by societal norms, institutions, and discourses. Ziggy's experience of being treated a certain way 'from the age of five, attending school, by medical professionals, teachers, and everybody else along the way' indicates he is subjected to external influences and power structures that tried to shape his identity and subjectivity. To demonstrate this act of moulding, his statement, 'what I was saying was invalid' reflects the power of discourse to invalidate certain voices and perspectives. In Foucauldian (1989) terms, this can be seen as an example of how certain knowledge systems and social structures marginalize and silence dissenting voices.

Another example of subject formation through marginalization can be seen in Bob's account, when he tells us that the teacher taught the class with her back to him. This approach to teaching is a form of subject formation, wherein the student is marginalized and excluded from active participation in the learning process. Foucault's (1982) concept of subject formation emphasizes how individuals are shaped by external forces and how they come to understand themselves in relation to these forces. In this context, the student is constructed as an outsider or 'problem' within the class. As Bob said, 'That year. I hardly passed. My projects were all late. It was terrible'. I believe this was not only Bob playing to a role, but, also possibly, a sign of his distress and disengagement with the world as he tried to sit in an identity that wasn't really his and which didn't allow for his emotional needs to be known (perhaps even to himself) or met throughout the day. However, these responses to distress will have easily been seen as part of

his role as the class ‘fleabag’²⁴ leaving the professionals free from responsibility. If the institutional message is that non-conformity (difference) is immoral, then the discourse on those who are different will be that they themselves are ‘immoral’, ‘dodgy’, ‘dishonest’, a ‘fleabag’ or just ‘wrong’.

Amidst these disciplinary and normalizing forces, both Bob and Sarah also reveal moments of resistance and support. The English literature teacher emerges for Sarah as an ally, offering support and encouragement. This teacher's encouragement and assistance represents a counter-discourse within the broader educational context. The student-teacher relationship here is an example of how power relations are not unidirectional; they can also be used to support and empower individuals.

When a new teacher enters Bob's life in grade five and expresses a desire for him to succeed, his identity changes from seeing himself as a ‘loser’ to an ‘achiever’. This transformation in the student's identity illustrates how education and the actions of those in positions of authority can shape the self-concept of individuals.

Those who have experienced shame in their childhood will often become highly observant in order to avoid a repeat of the experience. Subtleties, such as a look or silence, can quickly bring up insecurities. What, in childhood, were actual spoken messages by those in positions of power, in adulthood are silent messages remembered in the body, keeping us compliant. To understand the level of pain this can cause I come back to Bob's words – ‘what's the point?’. Whoever Bob was, he was being missed and living in a situation where he had no power to change that. Not all people survive this pain.

Jen describes being fired as a ‘trauma’. I think most people would find this understandable even without any additional context. However, Jen did provide context. Like every other participant, her story was about feeling misunderstood by those in power. What is also worth noting is that her termination of employment happened ten years prior to her interview with me - and Jen was still deeply troubled by the experience as she recounted it. In all that time she never went back to social work. *This was Trauma*. Every participant spoke about someone

²⁴ Fleabag is a term which means a ‘dirty’ or low-class place or person.

else's perspective being more legitimized than their own, and how those people often used their voice to apply their own account of who my participants were. This applied identity shapes how we see ourselves. As Toni Morrison (1993) says, narrative is 'radical', and it creates us at the very moment it is being created.

COMPETENCE VERSUS INCOMPETENCE (Conformity)

To understand how messages of institutional incompetency impact the development of the child, we can look at developmental psychologist Erik Erikson's eight 'life stages'. For Erikson (1950) the early school years (ages 6-12) are known as the 4th life stage. This stage is called 'Industry versus Inferiority' (de Vries, 2016). The term 'inferiority' implies comparison to one's peer group. With regards to the term 'Industry', Erikson (1950) is likely referring to a person's natural inclination towards industrialism - which we all have - i.e., our ability to get our basic needs met at an 'age-appropriate level'. But... what exactly does age-appropriate mean? If we accept the messages of Foucault (2006), it means that which the immediate society considers normal for the age.

All participants touch upon the ideas of normalization and the pressure to conform to established norms. Sarah is criticized for being quiet and 'daft' in class, which leads to teachers making assumptions about her capabilities and intentions. The expectation for students to perform tasks like showing their working out in math exemplifies how normalization and standardization are imposed within the educational system. Jen's excerpt looks at an employee's perseverance and effort to meet the job's demands. This reflects the ways individuals may adapt and respond to the power structures in their environment as they attempt to comply with the expectations placed upon them.

In his 1975 Collège de France course "Abnormal" Foucault asserts, "the norm' is not founded on intelligence, but upon that which those in power have chosen to legitimize or punish" (cited in Rocca, 2012: 197). A child of 5 might be expected to learn fishing in one country whereas in another country competence is evaluated by the ability to sit still in class for many hours of the day. When expectations are dictated by an institution, one's sense of competency is also dictated by that institution.

Bob starts with a strong image of power being deployed in a classroom environment when the teacher *grabbed* him by the ear and brought him to the front of the class. Foucault (1979) looks at societal involvement as being necessary for an effective punishment, which seeks to shame the perceived offender and coerce onlookers into ready compliance.

On her Facebook page, author and clinical psychologist, Naomi Fisher writes about behaviour charts used to evaluate a child's behaviour from a young age. Of this she wrote the following:

Children's names are moved from the sun to the clouds, or from green zone to red zone, depending on whether their behaviour is thought to be acceptable or not... The whole system assumes that the reason for their behaviour is that they just aren't trying hard enough, and that we can make them try harder by putting their name up there for all to see. ... We know from research that very young children can rank their peers by how well behaved they are, and how popular they are.... These charts put the onus to change on the children who already find things hardest. It tells them, again and again, that they are a problem and they aren't trying hard enough. It ignores context and why a child might be behaving like this. Instead they are shamed.... They aren't just not working, but they are probably causing damage. Using public humiliation to control behaviour has side effects.... These experiences stay with some children for the rest of their lives. They think of themselves as 'not trying hard enough' or 'lazy' (September 2023)

This ties into my earlier point that punishment requires an audience. Foucault (1975) is clear that the deployment of such coercion is not a conscious act on the part of the deployer, but an instinctual move or simply an unconsidered part of the culture in which they work. Whilst Bob's teacher might believe she was ignoring him for the purposes of teaching the rest of the class, or be following what is a common practice amongst other teachers, she was effectively: (1) leaving Bob on display for other students to watch. This public display of her power gives her more authority within the class; (2) Making a public statement to the class and Bob that he was worth less than his peers; and (3) Letting the other students know such shame is a potential consequence for them, and in effect producing more compliant students.

Although this situation has been manufactured by an institutional standard of competence, I would argue that for many children of today, Erikson's (1950) 'industry' is about managing to navigate *the* industry, without suffering wounds to their self-esteem. Bob had literally been separated from his peer group and sat opposite them creating an unspoken declaration of incompetence by comparison. Bob speaks of accepting his role as the 'flea bag' and that was 'the only way I could fit in.' For a time, Bob may have found that his competency was in being 'bad'. Taking up an allowed subject position offers us a way to not be fully extradited from society. But at the same time, it does allow for continued Othering. We can think of it as a conditional permission to remain, 'Okay you can stay. As long as you stay over there. Play your part'. I would say that *wondering* where or if we fit in the group is so deeply uncomfortable that accepting a subject position, even one we didn't want, is more bearable. Often a child tries to make the world feel safe by accepting that they themselves are bad or wrong and those in power (the adult or the majority) are good and trustworthy. We do it to survive, although it might mean relinquishing a healthy sense of self.

Scottish Psychiatrist, William Fairbairn theorized that children will decide they themselves are bad rather than accept that the world around them is unjust. This was called the 'Moral defence' in which Fairbairn states:

It is better to be a sinner in a world ruled by God than to live in a world ruled by the Devil. A sinner in a world ruled by God may be bad; but there is always a certain sense of security to be derived from the fact that the world around is good' (1943: 66-67).

Self-stigma becomes an act of self-protection to avoid feeling the pain of helplessness in an unjust world. This can turn justified feelings of anger into unjustified feelings of anxiety, self-doubt and self-blame. Jen feared she had been 'daft' or would be seen as dishonest. There was little to no permission to simply have had a misunderstanding or to voice the concern that the job advert had been misleading. In both cases the industry is protected by holding the individual responsible for perceived incongruences rather than making room for - or exploring - the different perspectives.

Maslow's 'Hierarchy of Needs' is a psychological theory proposed by Abraham Maslow in 1943. Maslow was an American psychologist and one of the founders of humanistic psychology. He introduced this theory in his paper titled "A Theory of Human Motivation". Maslow's hierarchy of needs is a framework that categorizes human needs into a hierarchical structure with each level building upon the previous one. The hierarchy is typically depicted as a pyramid with five levels:

1. Physiological Needs: These are the basic biological needs required for survival, such as food, water, shelter, and sleep.
2. Safety Needs: Once physiological needs are met, individuals seek safety and security, both physical (protection from harm) and psychological (stability, routine, order). If psychological safety is reliant on stability, then a child who doesn't feel they can control or predictably influence their environment will not have a sense of psychological safety.
3. Love and Belongingness Needs: After safety needs are satisfied, people seek a sense of belonging to their group.
4. Esteem Needs: Once social needs are fulfilled, individuals strive for self-esteem and recognition. This includes a desire for respect, achievement, confidence, and a positive self-image.
5. Self-Actualization: This is the highest level of need, where individuals aim to reach their full potential and achieve personal growth, self-fulfilment, and a sense of purpose.

It's important to note that some criticisms have arisen from other theorists over the years. Amongst those is the voice of psychologist Clayton Alderfer (1969) who argued that Maslow's needs can overlap and influence each other. This certainly seems to make sense when looking at how the denial of safety or belonging is likely to affect one's self esteem *or* how the denial of belonging could affect one's sense of safety. To that end, Alderfer also proposed that individuals might not progress through the hierarchy in a strict order. What I find is that Maslow has identified core needs which I believe are intertwined and are crucial for self-actualization. I believe that if these needs are readily met then development will happen in the right way for each individual.

SUMMARY

Boyle and Johnstone assert that:

Threats [to our core needs] experienced in childhood can have very long-lasting effects. This is because they limit vital opportunities for learning how to meet our core needs and for developing skills and supportive relationships that prepare us to deal with difficulties later in life. (2018: 198)

In this chapter, I have analyzed my interviews with participants using a trauma-informed Foucauldian discourse, highlighting how power is established and perpetuated through the use of language, the invalidation of voices, surveillance, disciplinary practices, and normalization in institutions like schools or workplaces. I have also shown how the actions and attitudes of those in positions of authority can have a profound influence on how individuals perceive themselves and their status within the group.

In the next chapter, Sarah and Bob are seeking to name their autism, but face similar disregard and restorying by professionals as they do so, whilst Ziggy tries to be heard by a doctor for a painful physical ailment. As you read on, I ask that you consider how the childhood experiences described in this chapter may have impacted the participant's ability to advocate for themselves as adults.

CHAPTER 8: WE CALL THAT PRIVILEGE

Some Tuesday in June 2020

Fresh out of the shower and smelling of soap, I sit in my living room wrapped in a beloved quilt one of my dogs scratched holes in. This is not a picture of grand wealth, yet I couldn't imagine being more deeply satisfied and blissful. It's a summer evening, sounds and smells from the garden come through the window while inside my husband is playing one of his free jazz vinyls. I am privileged to know this kind of contentment most days, privileged to have a garden to sit in when the shops and restaurants are closed during the pandemic, privileged to live in a neighbourhood where I can leave the window open on an evening. I think of people who don't have these things, whom I don't make a regular practice of thinking about. People, whom, if they are not thought about and not taken seriously, continue suffering while others, like myself, sit smugly in their sitting rooms on an evening ignoring that which they are ignoring.

The question of privilege and power is a strong thread throughout this work. In the last chapter most of my participants shared experiences from their early school years in which those in power were often teachers but could also be any adult in general. In this chapter the participants are sharing experiences from their adulthood, where certain professionals are still regarded as being in a position of authority and how this dynamic affects their attempts to get their needs met. One way in which this happens is that individuals with Autism Spectrum Condition (ASC) may experience barriers in accessing healthcare services, such as difficulty finding healthcare providers who are knowledgeable about ASC or who are willing to accommodate their unique needs. A study by Nicolaidis et al (2019) found that individuals with ASC reported negative experiences with healthcare providers, including feeling dismissed, misunderstood, and stigmatized.

ZIGGY

In the previous chapter Ziggy spoke about feeling his perspective was seen as less legitimate than that of the adults or professionals. In this passage Ziggy continues to demonstrate the

same sense of having his perspective be illegitimated even in adulthood. Here, Ziggy is telling me about a time when he was attempting to explain problems he was having with his leg following a surgery. The exchange, which took place over the phone, seemed to go badly. I suspect both doctor and patient will have had different understandings of what caused the breakdown. Below, I share Ziggy's account. It's important to know that mum was part of this conversation between Ziggy and the doctor and mum recalls some of the statements made by the doctor which I have included in the text below.

I KNOW MY BODY

I pointed out that I know my body
and that this isn't working
and it's causing major problems with physiotherapy
he just blatantly shut me down several times

'He was told he's hyper-sensitive,'
'he's got arthritis,'
'He has fibromyalgia.' (Mom)

The more I said,
"This is why you're wrong,"
the more he got his back up.

"I'll just end the conversation with you."

"Hey, I'm listening to what you're saying."

What I'm telling you is it's factually incorrect."

"Now, I don't appreciate your tone."

"I'm not taking a tone with you.

I'm telling you very straightforward."

"If you're not going to listen to what I said, --"

"I'm saying, I'm listening to you.

You haven't acknowledged the issue."

What is perceived as arrogance,

it's really just me knowing myself,

and being assertive enough to be able to say that.

.... That is just a skill,

It's not really greeted with great admirability.

that comes across as being arrogant,

self-righteous.

What's that word?

Demeaning, dismissive, totally rude, obnoxious, you name
it.

I've been called them all.

but I know I'm not those things.

What I experienced of Ziggy's communication style during our interviews is that he can be both direct and divergent. *And somehow at the same time!* He tells me that his mother calls his 'train of thought' a 'bullet train' 😊. I understand Ziggy to be doing two things: (1) he is trying to establish the facts, which should be able to stand on their own merit regardless of tone of voice or phrasing; and (2) He is offering a witness to give credibility to his version of events. I can hear the power dynamics at play here. Ziggy's offering of a witness, although this may have been perceived as a threat to the doctor, was likely born out of insecurity and a need for external validation after a childhood where those in power made him feel his perspective was illegitimate.

Ziggy begins to describe the back, and forth which took place over a phone call. The first thing Ziggy remembers is the surgeon informing him that they were taking time to call him during a pandemic. The message I hear in this is that the professional would like Ziggy to feel grateful for his time. There becomes a social and moral element to consider because there was a pandemic and health care professionals were working harder than ever. For me this could become a discussion about how funds are allocated within the current government, this then draws on a discourse of gatekeeping resources of time and money and compassion fatigue professionals suffer due to exhausting working conditions.

What Ziggy shared after this section of the interview was that the surgeon later hears from the physiotherapist the same information Ziggy had been offering. After discussing Ziggy with another professional, the surgeon finally accepts and acts on the information. There may be an argument to be made for the surgeon needing to confirm information with someone who has trained in a particular field, but the act of shutting down the patient when they are explaining their experience goes beyond simply seeking further consultation. In line with Foucault's (1979) theory of docile bodies - to be a 'good' patient Ziggy must be submissive, trusting and readily compliant. This action is underpinned by the discourse that 'The patient cannot know themselves'.

Foucault (1979) would assert that if this is challenged, the doctor's potency as the 'expert' is lost. In line with the self-protecting nature of many discourses, Ziggy's confidence is treated as belligerence - permitting the doctor to threaten to discontinue communication, which might challenge his authority whilst maintaining that even that act would be a logical consequence

of the patient's non-submissive behaviour. In this way active consent to the process of professional involvement is actually discouraged.

As he recounted his experience to me, Ziggy talks about the 'tone of voice' he used when on the phone, stating that he was 'calm' - but the professional accuses Ziggy of 'taking a tone'. The medical labels mentioned in the text, such as 'hyper-sensitive', 'arthritis' and 'fibromyalgia', are examples of medical knowledge that is being used to categorize and define Ziggy's condition. This knowledge is wielded by the medical authority to shape the narrative and potentially invalidate Ziggy's experience. The exchange of words and tone in the conversation are a manifestation of power relations. The doctor attempts to control the discourse by ending the conversation and policing Ziggy's tone, while Ziggy insists on his right to speak and be heard.

I find that Ziggy is trying to be heard by doing a typically autistic thing of seeking to repeat what he believes was said between both parties in a previous conversation. In my view this might seem a little like isolating out the facts of what was said so both he and the doctor can look at it objectively. However, often the act of telling someone you can repeat their words, amid a disagreement, is received as an act of hostility rather than an attempt at bridging a communication gap. It *may* be that Ziggy was upset and that this upset was heard in his voice and that Ziggy himself was unaware of this. Or it may be that Ziggy was completely calm and the doctor simply misjudged Ziggy's tone through his own frame of reference about direct communication.

What Ziggy is sharing here, which I suspect is a common experience amongst minority groups, is confidence and self-assertion being judged as 'hostility' or 'abuse' by the people in the majority group. As Ziggy puts it, 'demeaning, dismissive, totally rude, obnoxious, you name it. I've been called them all'. This is even easier to do when the minority group is linked to a psychiatric condition. But it is the last sentence that I find most indicative of Ziggy's character when he says, 'I know I am not those things.'

Ziggy's repeated attempts to assert his own knowledge about his body and his condition can be seen as an act of resistance. He is challenging the doctor's authority when he states, 'This is why you're wrong,' and emphasizing his own self-awareness. I find it admirable that Ziggy's

discussion of his self-awareness and assertiveness as a skill represents an attempt to construct his own identity and resist the labels imposed on him by others.

SARAH

In the following passage, Sarah is telling me about her experience of first sharing her belief that she was autistic with her psychotherapist. A psychotherapist is often a safe non-judgmental person who clients might use as a first port of call to voice thoughts and experiences they may feel too vulnerable to share with others.

I KNOW SOMEONE WHO'S AUTISTIC

"I know someone who's autistic

and you're nothing like them

so, you can't be.

you have empathy" she said,

"I really think you're just trying to diagnose yourself"

"What do you know about autism then?"

"Someone gave me a book

I've got it somewhere."

"I'm trying to tell you, my experience."

"Well, I know people

who are much *more* autistic than you...

I know someone

who can't even speak to the parents at the school gate.

Why are you doing this now?

When **you've got a successful career?**

How would this make a single bit difference to you?

You're talking yourself into a diagnosis."

If anything, I said

could be in relation to autism.

She would say,

"Well, it's not that.

It's this...

You're just trying to diagnose yourself."

Everything.

Every

single

thing.

"It's nothing to do with autism.

I don't know why you're talking yourself into this diagnosis."

Right away the therapist starts by telling Sarah that *she knows* someone with autism and, because Sarah does not remind the therapist of that person, Sarah herself can't also be autistic. The phrase, 'You're nothing like them' places the responsibility on Sarah to present the way the therapist believes an autistic person should. Ironically, the therapist then draws upon the common assumption that an *autistic person* can't be empathic which, in itself, sounds very unemphatic because Sarah's therapist is privileging the 'book' she has somewhere, over Sarah's lived experience.

This illustrates how the therapist attempts to establish herself as an authority on the subject, using her acquired knowledge to question Sarah's self-awareness and understanding. Her use of the book as a source of knowledge is a demonstration of how knowledge can be used as a tool of power to shape and control discourse. This reinforces the idea that the interlocutor is attempting to assert authority over the conversation.

Not knowing what book the therapist is referring to, I *suspect* this to be an example of how medicalized views on autism trickle down to less medicalized professionals and members of the public, affecting how they view and respond to autism. The overriding contemporary clinical discourses I listed in Chapter Three were that people: (1) lack self-awareness and awareness of others (Have difficulties with Theory of Mind or are lacking in empathy); (2) lack self-control (Have depleted Executive Life Functioning Skills); and (3) are not able to see the big picture and function in the world as it is (Have a weak central coherence). All three declarations came from *non*-autistic researchers over 40 years ago but continue to dominate the mainstream understanding of what it means to be autistic. Whilst society's thinking does slowly evolve, the early damage created by these messages is still evident in transactions such as the one above. This is part of the wider discourse that the patient cannot know themselves and that differences must be evident to the observer. Sarah appeals for the empathy she seeks by reminding the therapist 'I am trying to tell you, *my* experience'. The therapist rebuffs this by making the point that she knows people who are much more autistic, another nod to the notion that differences must be precise, and a low-key suggestion that it is wrong to seek a diagnosis if one does not have the type of autism that is obvious to others.

The therapist refers to a school aged *child* who goes mute at the school gates. Ironically Sarah's early childhood experience was heavily shaped by her own silence and frozen responses at

school. I also consider that the school gates are a busy place and a time of seemingly chaotic transition. I assume Sarah's therapy sessions were conducted in a very different environment.²⁵ I wonder if the therapist has spent any time considering that adults, whether autistic or not, will often present as very different from their childhood selves or that the environment would make a huge difference to one's presentation.

It's particularly interesting that the therapist's next statement is to question why Sarah would want a diagnosis if she has a 'successful career' as if that should stop someone from wanting to name their difference. This statement very much puts the emphasis on the person's ability to survive in a capitalist society whilst dismissing their desire for self-understanding. This is then reenforced by, 'I don't see what difference this would make to your life now'. Ironically these judgments that behaviour and production are more important than self-understanding are coming from a psychotherapist who is arguably there to facilitate *exactly that* for the client.

I see the psychotherapist's challenge of Sarah to be another act of objectification. The expectation is that Sarah must submit to scrutiny and allow herself to be known by the professional rather than seek to know herself. This is further evidenced in the statement, 'I think you're just trying to diagnose yourself', which the therapist said twice as if that's wrong for Sarah to do. The unquestioned discourses I hear are: (1) Autistic people must have observable stereotypical traits and present as children or present as they would when under stress; (2) Autism is an undesirable subject position which is not applicable to people who have careers or demonstrate skills that allow them to achieve monetary success in modern culture; and (3) If you serve a function in society you don't need to know yourself further. However, Sarah repeatedly tries to assert her own understanding and experience, emphasizing that she is sharing *her* experience. This can be seen as a form of resistance to the interlocutor's attempts to label and categorize her. Here, Sarah goes to her GP to seek a referral for an autism assessment:

²⁵ I have a client who comes to see me. When we are working in the room it seems their autism is non-existent. When I see them walking down the road later, even from a distance, there is a tremendous difference in their gate. The autism suddenly seems visible when it almost wasn't at all in our room.

I'M ASKING YOU TO SEND A REFERRAL

“You can't be autistic.

You won't be able to be a therapist

and be autistic.

I don't need to send you for an assessment.”

“I've done so much research into this,

so, so much

this needs to be taken seriously

and for you to send the referral.”

“It wouldn't be fair for me to diagnose you.”

“You wouldn't be qualified to diagnose me.

I'm asking you to send a referral.”

That felt like a real stumbling block really.

I felt hugely judged.

Although not brought up in this excerpt, Sarah did mention to me that her partner was present for this meeting. The act of referencing another person as a witness was something that many participants did when sharing their stories and I will explore this further in the discussion.

What comes up here in this passage is that Sarah has gone to her GP to ask to be referred to someone qualified to assess for autism. Frustratingly, the GP makes an immediate assessment that Sarah *can't* be autistic, because in the GP's view autistic people could not be therapists. I have heard similar accounts from clients where doctors have made statements to the effect that people with ADHD can't complete university. An alternative way of understanding such statements is that the doctor is making the judgment that neurodivergent people are not as smart or as capable as they themselves are.

Worryingly, in Sarah's case, the GP felt so comfortable with her judgments about what it meant to be autistic that she didn't want to make a referral for Sarah to have an actual assessment. In the UK patients are allowed to request referrals for services and are legally entitled to receive the requested treatment within 18 weeks of the request - but there are likely unwritten rules that run counter to such laws, which I discuss later in this chapter. The GP says that she simply doesn't *need* to refer. Not only is this counter to the NHS guidelines, but this phrasing also dismisses the fact that Sarah is not bringing up a question of need, but rather making a request for her own medical welfare - which *she* has decided is important.

Sarah's GP rebuffs her a second time with a statement that it wouldn't be fair for her to diagnose Sarah. She says this, despite the fact that she is not qualified to make a diagnosis - and in any case she had already made an unofficial judgment that Sarah *wasn't* autistic and didn't seem to consider *that* in itself is unfair. Another way to understand this is the GP clearly had a personal opinion about whether Sarah could be autistic and was allowing her personal opinion to impact her professional role. To Sarah's credit, she restated clearly what she was asking for. As with being calm, marginalized groups often must learn to be transactional in nature, not allowing feelings about unfair dismissals or bias, to become our focus. It is often the burden of the minority that they must navigate the unquestioned assumptions of the majority that stand in the way of us seeing to our own welfare. Sadly, such assumptions can have devastating effects and, in this case, caused very real challenges for Sarah with regards to getting a diagnosis. Sarah stated that this felt like a huge 'stumbling block' and she felt really 'judged'. I can imagine the embarrassment of going to a professional to ask for help for yourself, but the person with the power to help must first agree that you are rational. Their opinion is not based on some objective measuring block, but their own experience of autism, even if extremely limited.

BOB

In the following extract Bob describes his earlier experiences of starting to seek a diagnosis. Similar to Sarah, he confides in a psychotherapist, but dissimilarly this was not *his* psychotherapist, but rather his friend. In this case I find that there is less responsibility for the therapist to remain neutral within this exchange. But the response Bob receives is still informative of discourses around autism and clinical labels.

SNOWBALL

Everybody said,

"Oh, people are all different.

you have to accept yourself.

There's a range of people

you're just in a range of people."

They are telling me these things to excuse it.

Nobody *would listen to my experience*

Nobody *ever helped me*

break that cycle.

Nobody *helped me*

break that snowball

I told a friend

who was a physiotherapist
that I felt like I had some kind of
social disability.

She said the same thing,
"Bob,
you're just not accepting yourself.
Everybody's different."

I didn't understand why I was different.

I just felt more and more alone
and inadequate,

can't even go to a doctor because

your leg is sore

and you find out it's actually broken

you can put on a cast

you know what's wrong.

what's **wrong** with me?

He's telling me nothing's **wrong** with me.

*Something's **wrong** with me.*

It just caused more and more collapse on myself

being harder and harder on myself.

I didn't get my diagnosis until after I met with my wife.

The only way I found out that I had autism is because

she saw a video about autism and said,

"I was watching this video about autism

the way these kids behave

is the way you described you behaved when you were growing up."

(At the Assessment)

I brought my wife to help back up

I blast things over with logic instead of telling how it is.

(Following the diagnosis Bob seeks therapy)

It's not like you get diagnosed and all your problems stop.

I did an intake with a therapist.

He was listening very carefully.

As soon as I told him I had autism

"That's not immutable to therapy!"

'we can't help you.'

it was a stereotype of autism,

what you couldn't do for it.

it made me feel like therapy is not for me.
nobody wants to talk to me,
They just either dismissed it (the idea Bob had autism)
or
they dismissed me
Instead of seeing me as a human being

he could help find meaning
That was a setback in terms of getting self-understanding

if you try to fit in
to minimize the damage
you get further pushed down.

If you raise it,
you're seen as a troublemaker.

Bob compares his visit to the GP to what it might be like to go to the doctor for 'a sore leg' and being able to have a doctor tell him definitively what's 'wrong'. To me this sounds like someone who is trying to find an answer which seems tangible and clear. Bob's desire for clarity is more in line with what one could expect of an appointment regarding a bodily ailment. This is an interesting comparison which nods to a discourse that 'psychiatric illnesses are illnesses like any other' - a discourse meant to destigmatize how we understand mental health. Although, as Boyle and Johnstone point out, this message tends to have the opposite effect as it cements the idea that difficult emotions are illnesses rather than acceptable personal deviations in how we think and respond to life as "these 'explanations also mystify the nature and causes of people's difficulties (2018: 49). I would say this 'mystification' is what gives rise to the 'differences must be precise' discourse. When it is accepted that interpersonal experiences are

as tangible and as measurable as the body, we start expecting to see that in a tangible way - and anyone who doesn't live up to that expectation may have their experience of difference dismissed - as was the case with Bob.

Whilst well-intentioned, Bob's friend has very neatly illegitimated Bob's right to engage with the discourse of his choosing, at the same time telling him '*everybody is different*'. On one hand it feels like they are rejecting Bob's autonomy to consider that he has a 'social disability', because they take the seemingly positive view that we all have difference. But what this doesn't leave room for is what to do when someone wants to acknowledge and name the ways in which they feel different. Bob goes on to use the word 'alone' which pairs with the phrase 'nobody helped'. He used the word 'nobody' ten times in our interview as he described his experience of seeking answers and understanding. His repeated use of the words 'alone' and 'nobody' speaks to the isolation Bob experienced during this time of trying to understand himself. In lieu of finding this understanding, he repeatedly uses the phrase, 'Wrong with me'. As in 'What's wrong with me? He's telling me nothing's wrong with me. Something's wrong with me. They are telling me these things to excuse it'. It sounds almost like they were purposefully refusing to help or put in the effort to understand him. Bob experiences frustration and isolation because his self-identification as someone with a social disability or autism is repeatedly denied or dismissed. But Bob resists these dismissive attitudes and seeks validation for his self-identity.

Finally, Bob receives his diagnosis and then begins the task of seeking to reflect on what this *means* for him. Ironically, after managing to get an autism diagnosis, professionals dismissed him because in their minds, he was now *too* different.

The term 'medical gaslighting' is believed to have been coined by the patient advocate and author, Dr Adam Kay in *Gaslighted by My GP*. Kay (2017) speaks to the experience of patients dismissed, disbelieved or invalidated by healthcare professionals. A study by Woods et al. (2017) found that medical gaslighting was associated with increased psychological distress, including symptoms of anxiety and *hopelessness* - meaning medical gaslighting can lead to a breakdown of trust in medical professionals and healthcare systems, which can lead to avoidance of necessary medical care and further negative health outcomes (Jones et al., 2019; Molloy et al., 2019). In line with these findings, not only did Bob not get what he was looking

for, but this experience likely left him feeling deflated to the point that he didn't continue seeking to get his needs met. As he said, 'I didn't think of just trying somewhere else'.

The label of autism became bigger than the person in front of the professionals, who was previously seen as not different enough. At first the message is, you can't be autistic because you don't fit our understanding of it. Then the message becomes, 'if you're autistic then you must be all the things, we understand autism to be'. Bob brings this to the point in three statements: (1) that he wasn't seen as a 'human being'; (2) he wasn't offered help to explore his experience; and (3) judgment was always made based on the 'framework' of the 'expert'.

First, I would like to acknowledge that Bob was not asking to have his autism treated. The assumption from the therapist was that it is something to be treated. That in itself is very telling of how the therapist sees autism. If we were to replace this with another protected characteristic like sexual orientation, gender or ethnicity, this statement would be seen as discriminatory.

Even if Bob had wanted to 'treat' his autism, the way this is phrased makes any failures of therapy the fault of the autistic person rather than the therapist. Alternative ways of phrasing could be that 'therapeutic modalities haven't developed a method for working with autism' (still dehumanizing as it misses that Bob is a person, but at least it would put the failure with the field of study rather than the autistic person); or, the therapist could have said, 'I am not aware of....'. Again, this misses the person, but would place the failure with the professional's knowledge rather than with Bob. The unquestioning way in which such statements are made signifies how deeply embedded this biased thinking is.

Bob's language - that spoke to his own psychological annihilation - were the words: 'cycle', 'Snowball', 'More and more', 'Collapse on myself', 'harder and harder', 'Wrong', 'Wrong', 'Wrong'. Bob used the adjectives 'Inadequate' twice and 'Stupid' to describe how he was feeling, stating that as he continued to not get answers, 'It just caused more and more collapse on myself and being harder and harder on myself'. Bob's repetition of 'nobody' underlines the circular nature of his distress and his sense of isolation in the world. I note that when Bob was speaking about what he had wanted from therapy the words he used were 'meaning' and 'self-understanding'. Another way to say this is that he wanted to create a cohesive narrative that

fit with his felt experience, because for many decades he was living with the narrative others had applied to him.

Foucault explains that one's sense of self develops in juxtaposition to authorized discourses. He claims that 'historically singular experiences' were supported by the *acceptable agreement* between one's inner experience and the authorized discourse and acceptable subject position, known as the "tripartite nature of experience" (Foucault, 1994: 3). If that is accepted, then we can conclude that one's sense of self is diminished in persons who have experienced pervasive incompatible narratives throughout their lives. If Foucault's (1994) 'tripartite nature of experience' is not acceptably met, then this would lead an individual to have a fractured sense of self. Research conducted by Matos and Pinto-Gouveia (2017) has demonstrated that the chronic break down of the self leads to the same responses as physical-threat traumas. Afuape (2011), a Nigerian, British-born psychologist working in London, writes about how narrative shapes our understanding and experience of traumatic events noting that the story itself, the act of stopping, choosing how to tell the story, and solidifying the experience in a particular way influences the individual's ability to cope and process their experience.

Bob wasn't seeking therapy for the autism. He was seeking therapy for himself. The clinicians didn't seem to consider that an autistic person might be impacted by the world around them, just as anyone might be. The understanding is simply that an autism person must only be seeking to address the autism. The undesirable trait.

This illustrates the Foucauldian concept of bio power in which the professional is positioned as the expert. The actual person is missed in all scenarios. The subject has little say in what is true of them. The subject's autonomy, rather, is in choosing the best available position within the discourses offered.

For Bob, early childhood discourses offered him the position of 'troublemaker', 'flea bag' but also, at times, 'achiever.' My sense from sitting with Bob was that he continued to feel incomplete and in need of further understanding of his experience of self in the world. This need might have been born of many other nuanced discourses, including a silent understanding of difference both within institutions and outside of them. What remains clear was that Bob went into his adulthood having a need to find an acceptable agreement between

his own sense of self, the sense others were making of him, and an acceptable, non-punitive, discourse within society. Unfortunately, as with all positions, there are limits. Finally, having achieved his explanation, Bob *continues* to use the word 'nobody', as in 'nobody wants to talk to me.' Whilst his own need for a start at self-understanding may have been met and an acceptable explanation for his differences is now on hand in new ways, he is again alone.

JEN

A COG IN A MACHINE

Managers.

GPs

anyone in any authoritative position

need to be mindful of their approach.

I need

a feedback cycle.

A person to be

open

communicative,

like, 'you do understand.'

Unfortunately,

It's very objective driven.

people are not seen as people.

They are seen as moving parts.

a cog in a machine.

I was formally diagnosed autistic at 31

Had I known earlier

I worry it would have had

a suppressive influence.

‘You’re autistic.

you can’t cope with University.’

legally employers cannot discriminate.

They’ll find other reasons

‘Well we’ve got someone else

who’s better qualified.’

IE, ‘not autistic’

I genuinely think my life trajectory

would have been quite different.

In the first block, Jen is drawing attention to people in positions of authority as she mentions managers, which is the primary authority figure in her story. Of interest is that she also mentions GPs which didn’t factor in her story, however I found this interesting because all the other participants had stories around medical professionals and their interactions with them. This makes me wonder if Jen also had an experience with a GP that she didn’t speak about.

What she's highlighting in this first block is how people in positions of authority need to be mindful of giving what she called a ‘feedback cycle’, which seems to be a sense of being

understood. I want to highlight that, as mentioned in Chapter One, 'understanding' was the major theme to arise from my MSc dissertation and seemed closely linked to a person's emotional wellbeing. Managers and GPs are common authority figures in adulthood, both having a direct impact on one's livelihood through employment status and health care. Jen is saying that these people specifically need to be sure they are understanding the person for whom they are facilitating the meeting of these needs.

In the next block, she goes on to say that, unfortunately, institutions are often extremely objective-driven, emphasizing efficiency and productivity. As a result, individuals within these institutions can start to be treated as mere moving parts in a machine, reduced to their instrumental roles. This phenomenon speaks to the act of objectification, a concept that Foucault explored extensively in his works such as *Discipline and Punish* and *The Birth of the Clinic* which delve into the idea of objectification in the context of institutional power. Foucault observed how individuals were viewed through the lens of scrutiny, often with a primary focus on what they could contribute to the institution's objectives, rather than their emotional or psychological well-being. To recap, in the previous block, Jen is talking about a need for connection then goes on to express an objectification as sitting in contrast to connection. People are judged by what they are perceived as being able to contribute.

Jen goes on to say that she was diagnosed in her early 30s but imagines that if she had had the autism diagnosis earlier in her life, it may have inhibited what she could have done with her life. She gives examples of what she imagines would have happened. People may have told her that she wasn't capable of going to university or they would have denied her jobs, all based on value judgments around how autism was seen.

Discussion

Jen and the others are speaking about how important it is to be properly understood by people who have power in our lives. In all excerpts, the participants are sharing experiences of not being listened to, understood or taken seriously by others who had influential positions in their lives. I do not claim that this breakdown sits only in one area of the communication process, but I do hold in mind that past experiences of invalidation may impact on the expectation of being heard as an adult. Beyond this possibility, I hear evidence of the same discourses identified in Chapter Six which are: 'Differences must present as clearly defined' i.e., not

containing any subtleties or perceived contradictions; If they are not clearly in keeping with the stereotypes of a disability, the person appears too capable, then 'Differences are due to immorality, laziness, badness or simply wanting to get away with something'. But I also hear evidence of another discourse: 'Autism is Undesirable' and a variation on 'differences must present as clearly defined', which I call 'We Over Pathologize'. I consider this to be a variation on the former because the idea that we over pathologize often stems from the belief that people with seemingly more mild or non-stereotypical presentations of autism shouldn't really have a diagnosis and this gives rise to the discourse we have started to over prescribe these labels.

In the discussion sections of my analysis chapters I explore how these discourses came about and how they harm or help. But, before I start to explore these discourses, I will discuss the dynamics of bio privilege and power which are core themes in this chapter and the foundation from which the discourses of this chapter have emerged.

POWER AND AUTHORITY

The participants are advocating for the right to define their own identity and experiences whilst others insist on defining their identity in an attempt to construct their subjectivity according to their beliefs. This is often done through a use of labels and categorization. In Bob and Sarah's case this is done by comparing their behaviour to their preconceived notions of what autism is supposed to look like. This reflects an attempt to fit the subject into a pre-existing category of what it means to be autistic.

Ultimately this is about authority figures saying what is true. As Jen points out - managers, GPs, and individuals in authoritative positions have the power to influence an individual's experiences, self-identity, and access to support or opportunities. Ziggy's excerpt furthers this as his text illustrates a power dynamic between patient and a doctor who is attempting to shut down his claims about his body and health conditions using dismissive statements like 'I'll just end the conversation with you'. This reflects the exercise of power and control over the narrator's body and health narrative.

Both Sarah and Bob's accounts highlight a power dynamic where the others attempt to assert control over their self-identity and understanding of autism. Statements, such as 'you can't be'

and ‘you’re just trying to diagnose yourself’, reflect an attempt to regulate and invalidate self-perception. Further attempts to wield power and control over Sarah’s self-identity are done by suggesting that she cannot be both autistic and a therapist. This assertion reflects the doctor’s belief that they have the authority to define who can or cannot be autistic, and by extension, who can or cannot pursue certain careers.

These excerpts show us how stereotypes and preconceived notions about autism affect the individual’s experience. When Bob’s potential therapist immediately responds with, ‘That’s not immutable to therapy’, it reflects a stereotypical view of autism as something that cannot be changed or treated. This can be disempowering and limit the possibilities for self-improvement or personal growth.

These stories bring up the issue of discrimination against individuals with autism, both legally and informally. As Jen’s excerpt suggests, the fear of discrimination may lead to concealing one’s autistic identity as employers might find alternative reasons to deny opportunities, such as claiming someone else is ‘better qualified’. This speaks to the hidden or concealed discrimination that individuals with autism may face.

To further coerce the individual into the wanted subject position, labels can be deployed as a form of discipline. As Ziggy says he has been called ‘arrogant,’ ‘self-righteousness’ and other negative labels. This reflects how individuals who challenge dominant discourses may be subjected to societal norms and expectations, often designed to maintain the power of authoritative voices.

BIO-POWER

In Chapter Three, I note that Karla McLaren refers to privilege as a type of mind blindness. For this reason, I offer the term ‘bio-privilege’ to describe the position most neurotypicals hold which allow them to dismiss the existence of ethnocentric thinking altogether. In her “Autism and Empathy: Part 1” blog, McLaren wrote:

The lack of awareness neurotypicals have — their blind acceptance of their world ‘the way it is,’ without concern for the needs of others — is called privilege in sociology. ... Neurotypical privilege relies upon the same unaware and insufficient reasoning as racial privilege does: if I don’t experience the sound of the dryer next

door as being extremely loud, then it shouldn't bother you, and you certainly shouldn't start rocking, flapping your hands, hitting yourself, or pulling out strands of your hair in order to deal with the aural overload (June 2011).

Often the professional helper's genetics grants them the credibility of being 'normal' whilst society grants them an understanding of being the benevolent authorities. Some professionals then comfortably accept this discourse that they are entitled to judge and reject attempts to check their privilege.

In "A Thinking Person's Guide to Autism", autistic blogger, Kassiane Sibley wrote:

When I sense professionals' actions are shaped more by cultural messages, and their sense of self is dependent on me being the grateful recipient of their good intentions, I find that scary and unpredictable. The risk, should I offend them, is that they become cross with me for telling them how I experience their treatment (November, 2019).

The idea of 'checking our privilege' gained popularity in 1988 owing to a paper written by women's studies researcher Peggy McIntosh, in which she listed out types of privileges a person might have. Decades later McIntosh gave an interview in the *New Yorker* in which she spoke about what led her to write her paper on privilege. She recalls the shock of hearing disparaging remarks about women's studies from male co-workers who seemed otherwise extremely nice, they were even the enlightened men who attended lectures on women's studies, whereas others simply ignored the topic all together. McIntosh writes:

...I found myself going back and forth in my mind over the question, Are these nice men, or are they oppressive? I thought I had to choose. It hadn't occurred to me that you could be both. And I was rescued from this dilemma by remembering that, about six years earlier, black women in the Boston area had written essays to the effect that white women were oppressive to work with. I remember back to what it had been like to read those essays. My first response was to say, "I don't see how they can say that about us—I think we're nice!" And my second response was deeply racist, but this is where I was in 1980. I thought, I especially think we're nice if we work with them (Rothman, 2014: 48).

The above passage is an example of a contradictory discourse in which a person has a surface level understanding of which discourses they consciously agree with, but at the same time they carry *deeply* embedded 'normalized truths' from older discourses. Foucault's (2018) 'genealogical' approach examines the historical development of power and knowledge, revealing the contradictions and transformations in societal norms and practices over time. I find that when there are contradictory discourses, it is because one belief is so deeply embedded that it remains even when it is challenged on a logical level. This is what would be called 'unconscious bias', a bias held outside of the person's awareness. The fact that this can happen without awareness is what makes the power imbalance between 'expert' and 'individual' so crucial. Foucault (1982) saw conditioning individuals to conform to *subjective* societal standards as the primary function of biopower. This conditioning was accomplished by observing the object, examining their way of being and making a judgment about what constitutes right behaviour or right thinking and enforcing that behaviour through acts of coercion, often reframed as 'treatments'. As Dusenberry notes, trying to maintain expertise over such groups has:

real and dangerous implications for those who differ biologically in that they remain under-represented in health research and the medical professions, but it also has equally real and dangerous implications in the way medicine is socially enacted (2018: 37).

Ziggy's extract is important as it demonstrates how power dynamics might play out, even when it isn't about discourses on autism. Rather Ziggy's experience looks at the power imbalance between the patient and the doctor. In Ziggy's excerpt the doctor accuses Ziggy of sounding hostile. Ziggy considers that he was direct and confident, yet this was interpreted as hostility. I imagine there are different possibilities as to what was going on.

One possibility is that the doctor resented how he was spoken to and interpreted Ziggy's directness as hostility. Comparatively, speaking about the experience women of colour (WOC) sometimes have when accessing health care, medical physician, Dr Prasanthi Purusothaman says:

Let's take an example of a WOC who has a non-English-speaking background and is unable to articulate gently. Perhaps her voice is raised as this is normal in her culture, and the immediate deep-seated belief of the clinician can be reflexively triggered. I can easily see how this is the perfect recipe for projection of inconvenience and frustration onto the patient, affecting optimal care (cited in Nicole Singh, August 2021: "The Lingering Impact of the 'Hysterical Female' on Women of Colour").

A second possibility could be that the doctor was aware of Ziggy's autism diagnosis. I believe this was the case and he had a prejudgment that autistic people are likely to be argumentative. This seems a common prejudice. If this was the expectation, the doctor may have been hearing hostility before it was truly present. Research conducted on UK practitioners found that general practitioners often demonstrated a good understanding of clinical descriptions of autism but felt hesitant in their abilities to engage with autistic people in their roles (Turnock, Langley and Jones, 2022; Unigwe et al, 2017). Unfortunately, my experience tells me that such insecurities on the part of the professional can lead the professional to projecting persecutory roles onto the autistic person, and if then the person is naturally direct or blunt even without actual hostility it elevates that projection. Rita Jordan echoes this sentiment on the British Psychological website:

we need to understand the 'typical' biases we show when analysing behaviour. Such biases mean that our conclusions are often misleading and contribute to the feelings of inadequacy that many carers feel when faced with untypical individuals, such as those with autism. The (professional's) response may be to resort to bullying, to try to re-establish control (May 2019).

Unfortunately, the person in power can then consider any rupture as supporting evidence of their original judgments about the autistic person. As is noted in Unigwe et al – "see, I said they were difficult (2017: 445–452.)

I also consider that all three of the possible explanations could have come together: Ziggy was frustrated, the doctor expected that an autistic person's frustrations will always be expressed

in an aggressive way, *and* he used his privileged position as the doctor to shield himself from the expected aggression. The blame is then put solely on Ziggy as the doctor threatened to end the call leaving Ziggy with his needs unmet.

CONTRADICTORY DISCOURSES

What immediately becomes apparent for me in Sarah and Bob's excerpts are that all people initially rejected the idea that Sarah or Bob could be autistic. It's important to note that these people - Sarah's therapist and Bob's friend - were not familiar with autism in either their personal life *or* work. All people who declared their opinion of what it meant to be autistic did so based on stereotypes they held about autism. Both Bob and Sarah, when seen by qualified diagnosticians with experience in the field, were given the label of autism.

The fact that the participants could name their experience was already a counter indicator to the idea that they might be autistic because this challenged the stereotype that autistics lack self-awareness. The autistic person simply isn't given the same respect and trust to assess their inner experience the way a neurotypical would be trusted to read an eye chart and report back how well they do or don't see. And the discourse that we can't know ourselves is a self-protecting one. As Yergeau (2017) notes (1) They can argue that autistic people are not autistic enough to make claims about autism; and (2) they can likewise argue that autistic people are too autistic to make claims about autism. Any contradiction in our discourses versus theirs can be understood as a symptom of our innate disability as autistics.

Jen proposes that had she been diagnosed earlier in life she would have been met with more resistance to her desires for education and career. If we look at Bob's experience post diagnosis, we can see that once the label of autism is given then the view others take of Bob changes to fit with the perception of what it means to be autistic whilst continuing to miss Bob as an individual. Previously, Bob was seeking a subject position to give him a 'framework' to explain his way of being to himself and others. Whilst a diagnosis can serve as our 'papers' which we can, *in theory*, pull out when challenged on our rights to participate in society – in reality, identifying as autistic can also lead to different limitations because psychiatric labels almost always come with an assumption that the holder of such a label is not functioning as they should: they are disordered. So, with this label we can say we are not purposefully awkward, instead we are *unintentionally* awkward. The step forward is the reduction in blame discourses;

but in their place new discourses about people who hold unintentional differences emerge. The idea that distress is due to an unintentional way of being and cannot be treated is common. As Bob said, *'They just either dismissed it or they dismissed me'*.

Author of *Authoring Autism*, Melanie Yergeau (2017), states that once she had her diagnosis her life was able to be framed by others in terms of disability. The language used to talk about her actions became clinical terms constantly pointing to something nonintentional, such as 'stimulatory behaviours' to describe hand movements. We do not use this term to describe people picking at their nails when they are nervous, tapping their foot to music, doodling when bored or stroking a pet for the pleasure of it. These activities are not seen as attributes of a disability. Yergeau shared that after her diagnosis quoting lines from her favourite movie was suddenly described as 'Echolalia'. Again, we do not use this term when a non-diagnosed person quotes their favourite lines from movies.

This is interesting because the non-intentionality of neurotypical behaviour is largely ignored. Non-intentionality is often only recognized when the non-intentional behaviours look very different from social norms. For example: cursing when you stub your toe would be unlikely to be pathologized. Cursing when you have an intrusive thought pop into your head is more likely to be pathologized with labels such as 'psychosis'. In both instances there is an unintentional response to stimulus happening, but the issue isn't really about self-control, it's really about whether others can relate. The judgments are, again, about the opinion of the bio-privileged onlooker.

This brings me to another shared theme between Sarah, and Bob which is that both were wanting to have their experience listened to as individuals. Sarah's therapist tells Sarah that she has a book on autism to which Sarah responds, 'I'm trying to tell you, my experience'. This reminded me of Bob saying, 'No one would just listen and take me as a person'. Jen builds upon this by saying, 'It's very objective driven. People are not seen as people. They are seen as moving parts. Sarah's therapist seemed to shift from 'you aren't autistic' to 'you're not autistic enough'. A nod to the discourse that if differences aren't extreme enough then acknowledging them is immoral, lazy and something worthy of disdain. For Foucault (1979), this objectification was a central theme in the mechanisms of power and control. It highlights how institutions, in their quest for efficiency, can inadvertently strip individuals of their humanity, reducing them

to mere tools or objects subject to scrutiny and control within institutional settings, often at the expense of their personal well-being and emotional experiences. Sarah's psychotherapist was not operating as part of an institution, but many people have internalized the message that recognizing difference in oneself is immoral without questioning the legitimacy of such beliefs.

UNINTENTIONAL GASLIGHTING

Counter to the attitude that identifying difference in oneself is immoral, is the belief that recognizing difference in oneself is stigmatizing which the individual needs rescuing from. In line with this, Bob is told to just accept himself. The message being that naming his autism is *not* the right way to accept himself.

Although 'gaslighting' as a term was originally used to look at intimate relationships between two people, some researchers argue that we need to expand an understanding of this behaviour to include social groups, particularly within the arena of healthcare (Sebring, 2021). In the same way that the term 'refused' suggests intentionality, so does the term 'gaslighting' - and I believe that it's important to clarify that - as Fetters states most of the time "when health-care professionals downplay or blow-off symptoms" (2018,: 131) this is not done with the intent of making the service user feel crazy. Rather it is done from a place of ignorance and privilege. As Sebring claims, "Gaslighting is one symptom of a larger problem in medicine, that is the continued privileging of biomedical expertise over lived experience" (2021: 131).

In her book, *The Sociopath Next Door*, clinical psychologist Maria Stout (2009) links acts of gaslighting to people with differently functioning neurology, claiming that neurodivergent persons are more likely to deploy gaslighting than neurotypical persons. In my opinion this is a prime example of an ethnocentric judgment, as it makes meaning of acts committed by someone from another group without considering the assumption in more depth. What Stout (2009) may not realize is that many autistic persons feel 'gaslit' by non-autistic persons. In an attempt to be more diplomatic than Stout, I would like to offer the term, 'unconscious gaslighting', which is not dissimilar to unconscious bias and acknowledges that the acts, even though potentially traumatizing, are committed outside of one's awareness.

Sarah describes feeling judged and experiencing her attempts to seek medical support as a 'stumbling block'. Sarah reflects on how her life trajectory might have been different if she had known about her autism earlier, while Bob speaks of feeling pushed down when he tries to raise concerns but feels isolated and missed when trying to 'fit in'. This illustrates how individuals who challenge prevailing discourses can face exclusion and highlights the emotional toll that such confrontations over self-identity and authority can have on an individual.

I think it is important to hold in mind the limitations of the medical sciences. Doctors are used to measuring and knowing – but autism and many other conditions cannot be measured or known through mere observation. I liken it to the experience of getting your sight tested. The optometrist fully relies on the patient to let them know how clearly they are seeing. They aren't waiting to see the patient bump into things before they agree to assess their vision. The appointment is extremely collaborative. The optometrist will have the patient look at many different slides, changing out the lenses, asking what the patient sees. The patient could always pretend not to see anything if they wanted a strong pair of glasses, but the optometrist assumes the patient is not seeking more than what they actually need. In Sarah's story I could hear an undercurrent of hostility that Sarah would consider seeking an autism assessment even though she is able to work. I find that this comes from the discourse of 'differences are immoral' or wanting permission to be different or have adjustments and tolerance is immoral, lazy, and a drain on others. Having glasses is extremely normal and doesn't raise hostilities, but autism is not there yet. We still tend to regard it as something that should be reserved for only a select few.

SAFEGUARDING COMPASSION

While Sarah's doctor might often be seen as having expertise power, in this instance it was beyond the training of a general practitioner to assess for autism. This meant that Sarah was not seeing the doctor for her knowledge but rather her position to process relevant information to another person on Sarah's behalf. This would be called 'executive power' because the doctor is being asked to execute a transaction on behalf of the patient. In this instance Sarah likely had more knowledge about autism than the GP, but the amount of work she has put in is simply ignored. Sarah aptly states that it is herself and the recognition of the vast amounts of research she has done which *needs* to be taken seriously.

One explanation was the position of bio-privilege the GP held, which allowed her to confidently dismiss what Sarah believed to be true of herself. But I believe there was more to it. GPs are stewards of resources. The message from the institution is to reduce costs. In this instance, Sarah is up against not only the power of the individual GP, but also the structure that requires Sarah to prove her request is worthy. In institutions like education or health there might be financial implications for resources spent assessing for autism. But actually, people will act as gatekeepers of autism, even when there is no financial implication for it. My feeling is that in these cases professionals are acting out deeply embedded institutional messages which they haven't considered challenging or discarding, even when they serve no purpose in the moment. Again, this reminds me of my earlier example in Chapter Four of stopping at the red light at an empty intersection. I see Sarah's therapist as an example of this. Sarah's therapist works privately and would not suffer either financial loss or scrutiny for accepting Sarah's assessment of her autism. Between the comment that others are '*more* autistic', and Sarah has a 'successful career', the message seems to be that 'wanting to understand yourself is unnecessarily self-indulgent if you're surviving in the world as it is'. Sarah's career was raised as a point by the therapist. Oddly, a private therapist will be providing a service that is all about better understanding yourself and most of the client base will have stable jobs. Like the suggestion that a diagnosis might be sought to 'let her off the hook' or so she can 'pull out the autism card' at work, immediately there is a link in the therapist's mind between autism and work resources, rather than Sarah wanting to understand herself. Bryony Shannon, the Strategic Lead for Practice Development at Doncaster Council, writes about "Why Language Matters" in her Rewriting Social Care blog:

Ultimately, because we've detached ourselves so completely, we've lost our identity too. We've removed all trace of humanity from ourselves as well as the people we're working with and become robots operating the social care machine. We've detached ourselves because we have no other option – the conveyor belt is moving too quickly for us to pause long enough to form any sort of relationship where we can truly understand people in the context of their lives, communicate at a pace that works for them, and explore a range of options together to enable them to improve their lives (9 August 2019)

The statement, 'I don't know why you're trying to diagnose yourself' suggests to me a discourse that 'autism is an undesirable thing'. In the passages above, the professionals were starting from a position of bio-privilege which dictates that we should all want to be seen as neurotypical, even in environments where being different is embraced as the norm. Historically the 'norm' has been: white, male, heteronormative, exhibiting morality in keeping with Christian values, neurotypicality and birth gender conforming.

I hear a moral judgment directed at Sarah who felt she was autistic but still sought to have a fulfilling career and relationships, to assert her autonomy *and* financial independence. My Don has made the point that a current discourse going around social media is a criticism of people who are perceived to be pretending to be disabled. But they ask, 'If people are really faking it so what? If someone is asking for accommodation why not give it to them?'. The way I understand this point is to say that when a person feels the need to go to lengths to pronounce themselves 'disabled' to get tolerance, perhaps the demands of the institutions are too high.

I find that when it comes to difference, there is a deeply distilled belief that *all* resources are limited, including things like: tolerance, self-reflection and emotional availability. I wonder if this is an internalized message from classroom experiences. School is most people's earliest experience with an institutional environment, where the ready compliance of students (who make up the masses) is integral to its functioning. Many people come away with messages such as, 'I had to do (.....) so you must too'. Or 'I didn't get a break with (...) so you can't either'.

There is an acceptance that the demands of the institution are an immovable thing and we simply *must* conform. I believe many people find the demands too much, and for some it might give rise to resentment if someone claiming to be autistic also seeks to be in mainstream society but with an added tolerance that others don't receive. The belief becomes the autistic person must either work *so* differently that they are clearly not part of the group, or they must stop being lazy and disruptive.

What I find interesting is Bob's statement, '*They are telling me these things to excuse it*' in response to his experience of dismissal when he first started seeking an autism diagnosis. From Bob's perspective it is the professionals trying to 'excuse' themselves from the burden of listening to him. There has become a game of tug of war over a *fear* of not having enough resources of compassion and tolerance.

THE NEUROTYPICAL MODEL OF PSYCHOLOGY

Another explanation is that Sarah's therapist and therapeutic modalities also rely on training that was centred around the neurotypical model for 'healthy' development and 'appropriate' adult abilities. Without meaning to, therapists often apply a neurotypical model of psychology. One term I have come across in my psychotherapy training was the term 'Games' coined by Eric Berne in *The Games People Play* (1964). According to Berne, a Game is an insincere act or gesture meant to convey a feeling the individual isn't secure enough to name. One Game is called 'Wooden Leg' in which the individual pretends to have an ailment and receives accommodation. Other Games might be when an individual 'acts' confused. During my training as a psychotherapist, I was once accused of playing a Game when I did not understand what someone was saying to me. However, the thing that I wasn't understanding wasn't being said explicitly. The woman speaking decided that *her* meaning would have been clear to anyone else, meaning other neurotypicals, but it wasn't to me - and when I didn't engage with guessing at what she meant - she called this a Game. However, to me it felt like she was the one playing the Game by not saying exactly what she meant. When I said exactly that, she then said I was being 'passive aggressive'. It is so interesting how language is deployed and who is allowed to use it and how it is understood - even amongst egalitarian Humanistic psychotherapists! The use of theoretical language in any profession will often position the speaker as the expert. The language gives the impression that these ideas are objective, factual and beyond the immediate comprehension of the untrained person and, should the untrained person seek to use these words, even if used correctly, it is regarded as an offence - thus, suggesting that the professional can know the client better than the client can know themselves. I cannot say why this should be so, but I can see that it threatens the power dynamic when lay people seek to educate themselves and ask questions or express opinions about accepted discourses. In my case I was not a lay person, but I was in the minority position and my use of theoretical language was still rebuffed.

Putting professional jargon aside, what we are talking about is one's *subjective opinion*. Should therapists challenge everything they themselves can't relate to? If a person states they are struggling with something, is it right for the therapist to push them to go further? Maybe in some cases the answer is 'Yes' particularly if that is what the client asked for. But in other cases,

the client may need to be heard and believed so they can develop the skills of advocating for their needs rather than ignoring them.

HOMOGONIZED DISCRIMINATION

In contrast to Sarah's therapist, I find that Bob's friend is seeking to discourage autism as an act motivated by a desire to save Bob from what she believes to be an unnecessary label for him, seeming to lean towards a discourse of 'we're all different'.

Thinking of Chapter Seven and how difference was regarded in the classroom environment, we might imagine that the discourse 'we're all different' could exist within a more utopian environment where children were encouraged to have autonomy. But what if, in this imagined utopian classroom, one of the children wants to use a clinical term to explain their way of being? Does the new rule become '*We don't do that here*'?

On the face of it, the 'we're all different' discourse seems to be *anti*-biopower - in which medicalized terms for difference are rejected. But I question the binary nature of Bob's friend's response. This way of thinking is similar to what Bonilla-Silva (cited in Unigwe, 2017) would call colour-blind racism, which suggests that race should be disregarded on the basis that we're all human. But taking this attitude then disregards the historical and ongoing structural disadvantages faced by marginalized groups. The discourses revolve around the idea that 'everyone is different' and that Bob should simply 'accept' himself, but these discourses serve to maintain the status quo and resist any challenges to the prevailing norms.

To me this discourse suggests that autism is not seen as something to be celebrated in the same way that race, sexuality, or gender are regarded as identities to name and celebrate. Being Othered and seen as so different we are not seen as human is deeply shaming. But at the same time having our differences ignored is shaming. The message I would take from having others reject my efforts to name my parts of self is: '*This* identity is so bad we don't name it unless we absolutely have to. It's an undesirable way of being'.

I think of how discourses on homosexuality have shifted over time. There was a time when people might have been encouraged not to name their sexuality if it didn't conform to the heterosexual norm, a time when homosexuality was still listed as a mental disorder; and now there might be an invitation to have a coming out party, a recognition that naming this for

oneself is an important part of self-actualization. Today many people are shocked to hear that it was ever listed as a medical disorder. But some of these *same* people give the message that there is no need to name autism. Gently whispering, 'Shhh, we're all a little different'. This too is shaming. We want our differences to be named - and seeking to name them in the way that feels right to us is part of healthy individuation. I believe that many people outside the group, feel 'autism' or other clinical labels are chosen as a default subject position which offers only a mildly better alternative to other punishing discourses, such as those explored in Chapter Seven. But assuming that someone only chooses a label because they have internalized oppressive messages denies them the autonomy they are trying to exercise in the now. This is unfair to the individual who might be making a well-considered choice for themselves. None of my participants expressed regret over their diagnostic label. All of them have had their diagnosis for more than a decade. To get rid of labels does not support an acceptance of difference, *it denies difference*. To describe this, I would offer the term homogenized discrimination.

SUMMARY

The discourse that 'resources of compassion and understanding are only for those with extreme difference' sits on a foundation of: (1) differences are the responsibility of the beholder; and (2) we must be economical with our efforts of adjustments, which relies on the medicalized challenge that in order for there to be a biological or neurological explanation, differences must be clearly defined. If differences are not extreme enough, then the other explanation is differences are immoral and the fault of the beholder. I believe that to have our quest for self-understanding rejected, particularly after a childhood where we were not understood, can cause more psychological harm than autism. Effectively, we are being told our perception of reality and ourselves is wrong.

This chapter demonstrates a clear power struggle where the participants sought recognition of their self-identification and understanding in the face of authoritative discourses that invalidate the narrator's experiences. The professionals on the other hand, asserted their authority to question and deny the participant's self-identity based on their own beliefs. This alludes to the prevalent discourse of objectivity and efficiency in various systems, such as workplaces, educational and medical institutions. In these environments, individuals are often

reduced to 'moving parts' or 'cogs in a machine'. This reflects a dehumanizing approach that can be disempowering and marginalizing, leaving professionals to act as gatekeepers of identity and authority. This chapter highlights a need to reevaluate existing power structures and discourses and shows a need for more empathetic and open communication, as well as a shift away from dehumanizing, objectivity-driven discourses in authoritative settings so that we as a society can ensure individuals are able to access the understanding and assistance they require. In the next two chapters I look at the impact such treatments have had on the participant's long-term well-being and sense of self.

CHAPTER 9: A WRONG SENSE OF BEING WRONG

A pattern of noticing things about the child instead of paying attention to what the child feels is a pattern of shame-inducing objectification (Broucek, 1991: 235).

In the last two chapters the participants shared some of their experiences of interacting with professionals who worked in education, social and healthcare fields. Over the years in which I have carried out my research, I have grown stronger in the view that the treatments received are not originating from the professionals themselves but from the institutions which they have trained in or work for. In this chapter I seek to look more directly at: (1) the lingering effects the participants have been left with; (2) the understanding they have made of their experiences; (3) how that impacts on their sense of self in the world; and (4) and what they have done to survive, before moving in Chapter Ten, to explore healing strategies.

Meaning might not be something which one can articulate in a straightforward way such as, ‘I understood that to mean...’. Often meaning is a felt sense in the body. A cold sense in the pit of your stomach that you are not safe, a hotness on your face that you are exposed and vulnerable, a lump in your throat that indicates you feel afraid to express your feelings or a trembling down your arms and into your fingers that makes you want to clench your fist when you have been wronged. Over time, to avoid such painful feelings, individuals might seek a *meaning* which minimizes unfairness by deciding they themselves are bad (Milton 2012). This might include: accepting their emotions are bigger and scarier than other people’s emotions; their perspective is odd or wrong; they are a burden and difficult to tolerate; or they are lazy and seeking to get away by making less effort.

BOB

In this first passage Bob talks about his fear of being judged as ‘wrong’ by others and how this has led to an experience of disconnection he’s felt to people in general throughout his life.

DISCONNECT

I was too anxious.

too disconnected
I felt so separate.
like it wasn't real
on the spot
my head feels full
like the first day of school
or having to make a presentation
or any time when I felt like I needed to perform
or connect.

*Anxiety,
if you've already got autism,
and you don't know what's going on with you,
and you can't connect with people
you're blaming yourself for it,
you're full of anxiety because of that,*

*I was writing my thesis
on authentic human presence,
I was telling myself,
"Why aren't I authentic?
Why can't I be
Spontaneous,
interconnecting with people.*

I don't always process things

I feel it

but I don't know if the other person feels it.

I don't know if I'm actually connecting with them.

I was always straining to not be stupid,

to not get it all wrong

I was always trying to fit in – Like school

and not alienate people.

if I'm talking about something

I'd just get a, " 'What are you talking about?' look."

that's not even their experience,

they can't relate to it,

there's just the disconnect.

therapy is not for me.

It's for other people,

but nobody wants to talk to me.

When I met the woman that became my wife,

it was really hard to move past all my fears.

Now,

I feel safe and connected with my wife.

I can tell her anything.

I've been married for 20 years.

she's great,

but sometimes she feels alone,

I'm not there for her the way I wish I could be.

I do the best I can.

I want to be there

but she can tell from my eyes that I'm done,

that I'm not really there.

I don't know what to do about that.

I'm so occupied with my inside experience.

I still have this deep fear that I'm wrong.

I'm processing things wrong....

that I cannot make room for someone else's experience.

in a really connected way.

I notice here that Bob compares having to connect to another person to having to 'perform'. Although I understood Bob to long for and enjoy connections with others, the way this is phrased makes it sound as though he is not able to be present in the moment forming spontaneous connections with others, instead he is hyper aware of what the other may be feeling or expecting and therefore his act of relating is more likely to be felt as a performance rather than an authentic connection.

In this first section Bob is describing the effect his anxiety had in causing him to feel disconnected and separate from the world around him, to the degree that he stated that things didn't feel real to him. Following on with the theme of disconnection from Chapter Eight, Bob is clear that to 'avoid disconnection', he 'stays inside.' To me this is a description of 'dissociation', a term that has many meanings within the field of psychology. Definitions of dissociation include difficulty forming memories, a sense of detachment from one's sense of self or a sense of detachment from reality or being in a dreamlike state (Michelson, 1996). I think the latter two are what Bob is describing.

Finlay notes that one commonality all understandings of 'dissociation' share is that they speak to different forms of detachment "whether from the external environment (e.g., derealization), from one's own experience (e.g., identify fragmentation) or from other people (e.g., disorganized attachment)" a term which comes from attachment theory (2012,: 428).

Bob uses the phrase, 'I can't draw on myself'. Whereas before, Bob was explaining that his external experience didn't feel real, in this passage he is talking about a disconnect from himself - not being able to use his cognitive resources in the moment. To better understand this, I refer to a theory called 'the window of tolerance' (2002), created by American psychiatrist Dan Siegel.

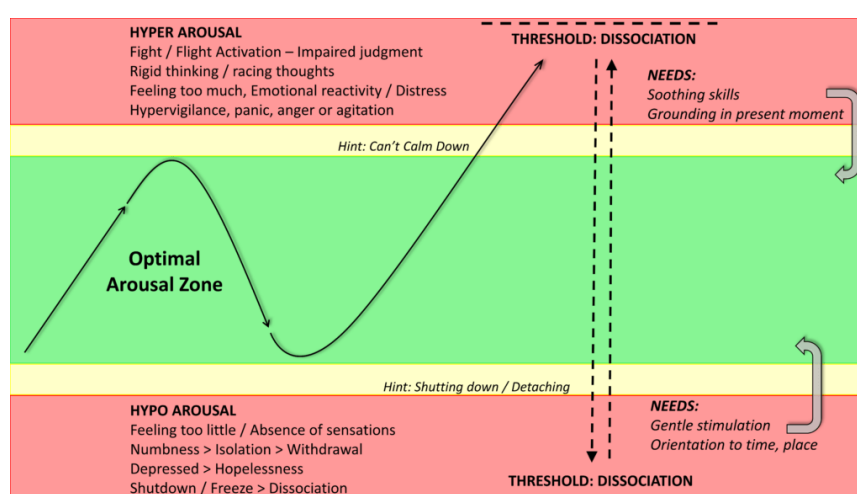


Figure 8: The Window of Tolerance²⁶

²⁶ mi-psych.com.au/understanding-your-window-of-tolerance/

As seen in the diagram above, there are three states of consciousness. There is hypo arousal at the bottom to mark the experience of being in a very subdued state. At the top there is hyper arousal to mark the experience of being on high alert. The middle state is our window of tolerance in which we can process our experiences and form solid memories. According to Siegel (2002), when we are in either the hyper or hypo arousal zone we have been pushed outside our Window of Tolerance. When outside of this zone, we are disconnected from ourselves and our surroundings and we will struggle to take in information or make thought through decisions or retain information. I believe Bob goes outside his window of tolerance when presented with an opportunity for contact and this is expressed in the statement, 'I can't draw on myself'.

Bob moves on to describing anxiety as a block to connecting with others and is clear that this is a bi-product of not knowing what is 'going on' with himself. This ties into what he was discussing in Chapter Eight where he developed feelings of self-blame and anxiety due to a lack of language to describe his experience.

In this passage Bob talks about a particular 'look' that he might receive from another to indicate he was wrong. For Bob, incongruence of experience is felt as a disconnect, a message of 'abnormality'. The 'what-were-you-thinking-look' Bob describes has been experienced repeatedly throughout his life. The look' reminds me of the medical gaze, a concept introduced by Foucault in *The Birth of the Clinic*. According to Foucault (1994), the 'medical gaze' refers to the way in which medical professionals objectify their patients by looking upon them with a theoretical curiosity rather than establishing a relational connection. The curiosity may not imply malice, but it does imply the recipient is regarded as a non-human, an object - but because the recipient is a person rather than an object, this is felt as a statement about their Otherness. The gaze or look in this case then signifies a disconnection.

Connection is a key theme with Bob and the other participants. It is mentioned repeatedly in multiple excerpts. This is also a key theme within the Power Threat Meaning Framework where Boyle and Johnstone (2018) assert that it is our connection to others which leads to our sense of self. I will expand on this further in the discussion section.

Towards the end Bob makes a distinction between the 'rational' and the 'emotional'. The agreement or disagreement between perspectives is seen as 'rational' and does not cause

shame to the point that Bob needs to avoid this. What Bob finds most painful is that others might not even experience what he experiences. I would conclude that when two people disagree about something theoretically but can still discuss the difference this suggests there is enough of a shared connection for discussion to take place. Disagreement then does not suggest a total disconnect of realities. What I understand Bob to find more distressing is the complete 'disconnection' which occurs when 'they can't *relate*...'. It makes sense that disconnection is conveyed in 'the look' which is silent, *not* articulated, discussed or named. Silence has been experienced by all my participants as a deeper, emotional experience of isolation. Bob tries to avoid the pain of this disconnect by 'staying inside'. But it sounds like the fear of rejection becomes a self-fulfilling prophecy because, whilst risk of rejection from the other was avoided by 'staying inside', Bob greatly reduces opportunities for connections to happen.

When describing his relationship with his wife, Bob links the words 'safe' and 'connected' with being able to tell her anything. To me this expresses the idea that Bob derives a sense of safety in knowing he will be accepted and attuned with a significant other, regardless of what he might say - 'I can tell her anything' - but then he reaches a point when, 'I'm done. No more room!'.

Sarah- self blame

Here Sarah talks about the repeated effects of feeling shamed in different environments, and how this has led her to the conclusion that something was objectively wrong with her because of the repeated experiences:

IT'LL HAPPEN ON A THURSDAY

All of that self-doubt

stuck from when I was younger.

That still really impacts me today,

I will have a strong feeling of

not feeling good enough.

I'll go into loads of self-doubt,

I certainly know when I was child,

I swallowed it whole.

I was stupid.

I did write the worst story in the world.

There's a reason why she shouted at me.

I've done something wrong.

Because that is how children take it.

*That was through primary school,
secondary school,
college.*

*It made me think this must be me.
there must be something wrong with me.*

*I felt like
I was different.
I was an inconvenience.*

*I didn't feel accepted,
or included,
or like I belonged
anywhere.*

*Throughout school,
I could only be described as hating myself.
the way that I felt about myself
was so awful back then.*

*Those experiences were really shaming.
then you're left tolerating the consequences of it
throughout the rest of your life.*

it'll happen at like-- maybe on a Thursday:

*It comes flooding in
'I'm stupid,'*

'I'm not smart enough.'

It's like I go back to that child place.

*I feel that huge sense of feeling sick,
panicked, headache, dazed.*

It was a way of being deeply shamed for who you are.

when feeling shame,

I would rather just the ground swallow me

or me just disappear

rather than be in this experience.

In this first passage Sarah moves from looking at how she internalized self-doubt as a lack of permission to set boundaries in her childhood to how it impacts her in her adulthood. Stating that even as she navigates her adult life, her earlier experiences cause her to doubt herself and to withdraw. Sarah mentions that messages from her earlier life come 'flooding in'. For me, this wording brings up images of someone being overpowered or 'swallowed up' by the negative messages.

Sarah then continues to look at how her body responds to the triggers in her adulthood, naming visceral feelings of being 'sick, panicked, headache, dazed'. On an aside, this feeling of sickness reminded me of Jane's daughter, Samantha, whom I wrote about in Chapter 5, who also spoke of feeling ill from anxiety. Like Samantha, Sarah also suffered from an eating disorder. Although I did not explore the root cause of Sarah's eating disorder with her, it leaves me to wonder if this could have been the same. Ultimately Sarah states that she would rather 'disappear' than experience the childhood feelings she associates with shame.

Sarah starts by describing some of the early messages she received at school. These messages were blaming and angry. The messages she states here are around her cognitive ability, but for Sarah this is also tied to her sense of having good moral character, as she moves from these messages to the experience of being shouted at in class - a public display of admonishment and humiliation while she 'sat in shame'. Putting aside the injustice to the child in that moment, experiencing this repeatedly would understandably lead to conditioning the person to doubt their cognitive ability and develop what might be described as anxiety disorders. This is often seen as part of the autism rather than as a response to the negative conditioning.

In the next passage Sarah states she has 'loads of self-doubt' as an adult, which cause events in the here and now to have a bigger effect than they might have done. If something triggers her self-doubt one day, she will spend the next three days in a hypervigilant state trying to correct the possible offence, which is often 'not being smart enough'.

Sarah starts to express feelings of questioning what others were seeing when they looked at her. In a way this is a reverse expression of the gaze which Bob spoke about, where Sarah is looking back, curious about how she is being judged. In both cases this represents a feeling of Otherness. In Sarah's case this speaks to her becoming what I have referred to earlier in this thesis as 'other-referencing' as she seeks to guess at how she is viewed and tries to prevent being viewed negatively.

In the next part, Sarah expands on being other-referencing as she says that she swallowed the messages whole, meaning she accepted the perspective of the other person. First, Sarah starts to doubt her perspective, wondering what others see, and then she moves on to accepting the messages she has been given about herself: 'I did write the worst story in the world' and 'I've done something wrong'. This serves as an example of how one can go from being other-referencing to self-blaming.

Jen

Jen gives a strong description of how rejection feels to her. I note that her language alludes to strong feelings that are often felt physically in her body:

A VISCERAL EXPERIENCE

Rejection is very much a visceral experience for me.

It's in the pit of my stomach
makes me feel like I'm gonna throw up
I want the void to *swallow* me up whole
Because that would be better
than experiencing rejection.

When we're in emotional overload
there's almost like a circuit breaker,
that puts us in a bit of a neutral state
to get us through that experience.

I see that as a mode of preservation.
rather than genuine unfeeling or uncaring.
Because we do feel things far more strongly.
And sometimes it can just get too much
and it's either:
feel it all and end up having a meltdown.
Or
cut it off for a period of time to continue.

I feel ashamed for having been rejected.

I should have done more

I should have done something different

I should have done better.

Unfortunately, that shame is not so easily erased.

Especially when it's so prevalent in your formative years.

Any life experience

good, bad neutral.

Shapes us.

and inform how we handle situations in the future.

I think the film Inside Out helps

to be able to explain experiences

identifying and articulating emotions.

You know the memory orbs

how they are coloured with the different emotions.

I look back

I lost my job.

That memory is coloured with a lot of shame.

Shame, I think from being made to feel insufficient.

It becomes a default state of existence.

It almost acts as a warning system.

I need to be careful.

Do not experience that feeling again.

My two settings are: guilt and worry.

If I'm not worrying about something,

I feel guilty that I should be.

It is absolutely exhausting.

Because as soon as you feel even a morsel of relaxation

the anxiety comes back.

you're almost made to feel bad for experiencing joy.

like I am worthless

I am a burden.

I'm, putting people out by merely existing.

Even if you were able to extract the trauma from our memories,
still holding ourselves up as OK
after any sort of shame or rejection
would still be very difficult.

So, when you factor in trauma.
it's sort of like a foundation that's ready to give way.
old wounds can open up.

In the third block Jen is echoing a point I made in Chapter One, which is that all our experiences have an effect on us. Jen has drawn what I consider to be an astute link, between that which can have a negative impact, such as feelings of shame and any other experience. Effectively what I understand Jen to be saying is that things happen, and we remember them.

Jen uses the film *Inside Out* (Docter, 2015) to illustrate her point about how we hold the meaning we make of experiences in our minds and bodies, and how traumas such as shame make us more vulnerable to future experiences of rejection which are difficult regardless of the past.

In the interviews, Jen talks about the 'visceral' sensations she experiences when rejected: 'It's in the pit of my stomach. I'm going to throw up'. I associate feelings of queasiness in the stomach as being connected to shame and fear. Following this, Jen refers to feelings of annihilation, the 'void' opening up and *swallowing* her. I note this is similar to the phrasing Sarah used when she spoke of the ground swallowing her up. I find the word 'void' to be interesting, as it is effectively a sense of nothingness. I believe Jen's sense of there being a void (which might swallow her up) to be indicative of her feeling worthless when believing she has been rejected by the other.

I also find it interesting that Jen uses the same term as Ziggy - 'circuit breaker'. I understand this term to mean a switching off or a stop in the flow of communication. In contrast to Ziggy, Jen sees this as something that happens in response to emotional overload rather than as a conscious act. Although in both cases it can be seen as a survival strategy or a boundary.

Jen goes on to explain that rather than seeing this as unfeeling or uncaring, this disconnect is likely to happen more quickly because 'we' (meaning the autistic person) are hypersensitive. The circuit breaker acts as a way to keep the person from having total meltdown.

Trauma triggers refer to stimuli that remind individuals of the circumstances present during a traumatic event. For people with PTSD, exposure to these triggers can elicit emotional, psychological, and physical reactions that mirror those experienced during the initial traumatic event or events. Although Jen doesn't go into detail about the origins of her experiences, it is clear that she is taking steps to avoid reexperiencing strong somatic responses to rejection, shame and worthlessness.

I write above that Jen described feeling worthless as a direct response to being rejected, then Jen goes on to state that she not only feels worthless, but she blames herself, 'I should have done something different'. This is what could be called meta shame. There is the shame of being rejected which is felt in the moment, and there is shame of *being someone who gets rejected* which is reflected upon after the event. One is the pain of a broken relational connection, and the other is the pain of thinking there is something flawed within the self that led to the break. As discussed in Chapter Five, Gottman (2006) would call this a meta-emotion that would also compound the trauma experienced.

Jen explains that to her, rejection means she is a 'burden...putting people out by merely existing'. This statement demonstrates the mechanics of how one becomes a 'docile body' (Foucault, 1979) through their internalized sense of guilt that they might be a burden if they are not conforming to the accepted social norms. Therefore, they seek to know and deliver that which is expected of them even when this is in conflict with their own needs.

In her book *A Person-Centred approach to counselling clients with autistic process*, autism researcher, Anja Rutten makes the point that because our sense of self is strongly linked to our social connections, having an autistic process will likely impact on how we develop our sense

of self-worth. Rutten (2014) proposes that people with autism will often feel that their ability to connect with others, such as early caregivers, is highly conditional and linked to their ability to conform to social norms.

ZIGGY

Here Ziggy talks about how he would protect himself from someone who wasn't listening to him. For the most part, Ziggy doesn't talk about how *he* might feel but rather how he is going to make the other person feel. I see this both as a meaning and survival strategy as this excerpt offers some insight into the meaning Ziggy makes of not being heard, although this meaning is framed as how the other will feel.

YOU'LL FEEL SO ASHAMED

If they say they're going to be flexible,

I won't have a problem.

What's causing major circuit breaks

and total power failures

is If they start with their attitude of,

"I'm right...,"

my hand will go in their face,

"No, stop speaking.

Not interested.

If you're not going to listen to me,

I'm not going to listen to you.

They're not going to hear any emotion in my voice

I get very direct, very blunt.

I get very rude,
very offensive
you'll want to cry,
you'll want to melt into a puddle.
You'll feel so ashamed.
I'm like, "Yes, you misjudged me, didn't you?
You really misjudged me.
It's not going to happen again, is it?"
I,
in no way,
am an idiot.

Ziggy starts by saying he will be fine as long as the person who he's speaking with is able to be flexible. What I understand this to mean for Ziggy is that he wants the person to make some effort to bridge any communication gaps that might exist between them by understanding that Ziggy has autism and what that means in terms of his needs. In the second half of the block, Ziggy goes on to say that what causes a disconnection for him is if they start with the attitude of 'I'm right'. This particular phrase reminds me of what Ziggy was saying in Chapter Seven when he talked about everybody else being right and him being wrong and everybody else being in charge. In his adulthood, Ziggy identifies that he has the power to discontinue his engagement with such people who might take such totalitarian positions of authority.

Ziggy says that he will cut-off communication by putting his hand in their face - telling them to stop speaking and that he is not interested. The phrase 'not interested' might tell us how he felt as a child when other people failed to understand his experience. Ziggy finishes that block by stating that if they do not listen to him, he will not listen to them which sounds, although blunt, also fair. However, in the next block Ziggy leans into what I would call a discourse of sociopathy, in which he links his bluntness to being rude and offensive. He then makes the assumption of how this might affect the other person. He says they will want to cry. They will want to melt into a puddle. They will feel shame. At the start of this block he clarifies they will not hear emotion in his voice. This speaks to the emotional disconnect he will exhibit towards anyone who is not going to listen to him. He is also linking such empathic disconnection to feelings of shame. But in this instance, he is the one asserting his power to shame the other.

In the last block Ziggy goes on to say, 'you misjudged me'. The question then is what might the judgment have been? With Ziggy's phrase, 'it's not going to happen again, is it?' I get a sense of a belittling tone in that question. To me this suggests that Ziggy is positioning himself as above and more powerful than someone who might hurt him. He places such power in juxtaposition of being misjudged or thought 'an idiot'. This tells me that the meaning he has made of such past treatments of not been listened to is that the other person has decided he was not important, he was not powerful and that perhaps he was not smart enough to insert boundaries that kept him okay. In other words, the other person could just continue on with their condescending behaviour without having to do any work to change. I understand Ziggy's excerpt to give insight into both the meaning he has made of such treatment and the survival strategy he has employed to keep himself safe.

DISCUSSION

These accounts of impact can be distilled into four main areas: (1) The fear and meaning the participants made of the looks they perceived from others. What participants made of their experiences was that others may view them as 'wrong' (Bob), 'an inconvenience' (Sarah), a 'burden' (Jen) and 'an idiot' (Ziggy); (2) The break in the communication cycle with others; (3) A sense of worthlessness caused by feeling disconnected from others; and (4) A feeling that not existing would be preferable to the visceral nature of shame.

A FEAR OF THE LOOK

As I write this I consider if the difficulty with eye contact is, for many, about avoiding ‘the look’? Or is it a fear of checking with the other for recognition, for fear that it might not be there? Or for fear that it might? Because a sense of self is also a sense of our right to take up space, be important, to get our needs met, and be acknowledged? When we have a diminished sense of self, we have a diminished sense of self-worth. Another way of expressing this is to say that in comparison to others we feel worth *less*. Worthless. For someone who has experienced a lot of disconnection, positive regard can be just as, or more uncomfortable, than negative regard, which sadly may be more comfortable owing to the familiarity of it. For even when it is there it might be like standing on a cliff edge. If there is understanding, validation or recognition with another, how long will it last? That is scary too.

I found ‘the look’ of interest for three reasons. The first is because of how this concept links to the Foucauldian (2001) concept of the ‘medical gaze’ which denotes an act of objectification. The second is because of the fear the recipient has of what is unspoken within the look. The lack of language goes further to suggest that you are *so* Other there are not even words to capture the Otherness. And because there is no clarified context for what is being scrutinized or seen as different it is more likely to be internalized as rejection of the core self. The third is that the look was brought up by all participants. It was the shared fear of the look, which all participants spoke about, that led to me placing Toni Morrison’s quote about language at the start Chapter Ten. As well as ‘the look’ all participants spoke about disconnection, both from others and from the self. I see the two as indicative of each other.

A RUPTURE IN SELF UNDERSTANDING

Being seen and understood correctly by others is hugely important to our wellbeing. I believe that everything I have discovered in my research thus far, rests on the primary argument that *people need to have a cohesive sense of reality* - a shared understanding between oneself and the world around them. Unfortunately, medicalized discourses on autism story us as a-relational or in lacking such an awareness that our environment should not have a significant impact on us. I note this benefits institutions and capitalistic structures which would have to spend resources creating an environment more conducive to the individual’s needs. Further to what I was saying in Bob’s section, Pierre Janet (1889), who wrote the first book on PTSD, called

such a split in realities ‘dissociation’. Joseph Breuer and Sigmund Freud (1893) called it ‘double consciousness’. All three men agreed this was a psychological *trauma* (Herman, 1994) - at least in part - to suffering from an incoherent story or an inadequate narrative account of oneself. As Herman (1994) notes, without the option for a ‘singular experience’, our choice is a split between our sense of self and the self the world sees.

This builds upon what I was saying in the previous section, that for many, self-blame - a decision that the self is wrong or untrustworthy - becomes the survival instinct that reduces the sting of injustice and replaces it with a less intense but deeper pain that we are wrong. The person who is in the position of privilege is likely to be oblivious to the mechanics of internalizing negative self-beliefs or the fragile relationship the oppressed might have to their own sense of reality, and they then use the oppressed person’s self-blame as confirmation of their badness – i.e., they obviously know they’re in the wrong because they’re so anxious or defensive. Meanwhile, the privileged are allowed a much simpler sense of self.

The child’s sense of connection to self and others will be contingent on their ability to meet these expectations. And so, wondering what the other expects or wants becomes the first (and second and third) instinct of the autistic person, with many becoming so detached from themselves that they are unable to have awareness of their feelings, stress limits, or to modulate their emotions through self-care and boundary setting. One might imagine this could easily lead to a vulnerability in adulthood. I take issue with the term ‘vulnerable’ when seen as an innate consequence of autism rather than a consequence of the fact that many of us have been conditioned to disconnect from our sense of self.

To consider how a disconnection from the self can be understood as trauma we might want to remember that the word ‘trauma’ is exactly that - a break. In the same way that a broken bone would be called a trauma, a broken sense of self would be a trauma. Some traumas are clearly predictable. If someone were to sever a limb, we could rightfully anticipate that this then results in a physical break. If someone has a hairline fracture in their tibia and continues to walk on it, we might consider that there is a small trauma and predict that a larger trauma will happen if care is not taken, but we may not know when or how bad this will be. This is unpredictable. It may not even be known that there is a hairline fracture and then the person may suffer a larger trauma. This is in line with what Jen said about pre-existing traumas from

childhood creating more of a sensitivity than others might anticipate. Traumas are not always predictable, and what may cause a trauma for one person may not for another.

POST TRAUMATIC STRESS

Not all traumas lead to what is called 'Post Traumatic Stress'. In this clinical term, the word 'stress' is meant to refer to emotional stress, so that this phrase can be understood to mean emotional stress that lingers after the traumatic event. Two people can be in a car accident and one person may experience lingering emotional stress around the event and the other not. A physical trauma or a physical threat may not result in an emotional impact, but we might anticipate that an emotional trauma or emotional threat is *more likely* result in lingering emotional stress. I would suppose that when an event has, by its nature, permeated our psyche in the first place, the impact is more likely to linger there.

TRIGGERS

Both Bob and Sarah make links between their early childhood experiences to somatic responses they experience in the here and now. When exposed to expectations of others, this might be described as emotional flashbacks (Walker, 2018) with past events being called 'triggers' - a term which dates back to studies of PTSD following World War I. A trigger is any stimulus, such as a sound, smell, image, or situation, that evokes a strong emotional response or memory. In the context of trauma, triggers can cause a range of symptoms, including anxiety, depression, flashbacks, nightmares, and avoidance of particular situations. All of these symptoms were mentioned by the participants in my study.

When stressors become cumulative and are associated with the society one is living in, this can traumatize. Stressors, one by one, may not seem worthy of the term 'trauma'. Being rejected or invalidated can feel awful but should it be traumatising or triggering? However, if you are rejected often enough - your body learns to expect this and likely gets stuck in a state of hyperarousal when out in the world - an experience described by many of my participants. As Jen states - all experiences good or bad contribute to how we think and how we experience the world. And as Jen and Sarah both noted in their transcripts - this is even more true when these experiences started in childhood. Affect dysregulation is thought to occur when early trauma disrupts the acquisition of emotional regulation skills, or negatively affects developing

neurobiology associated with downregulating distress - meaning people who experienced excessive hyperarousal in childhood would be more likely to experience emotional flashbacks in adulthood.

REDUCED SELF AWARENESS

In some survivors of early trauma, these deficits may lead to a generalized lack of knowledge about internal states and processes, as shown in Bob's excerpt where he talks of an insecure and unstable model of self and poor self-other boundaries, or such as Sarah described, 'I didn't have any boundaries when I was younger'. Such reduced self-referencing may also lead to difficulties in predicting one's own reactions or behaviours in various situations. Despite individual differences, difficulties in social functioning are common psychosocial repercussions of traumatic experiences. These range from social isolation, difficulty trusting, and detachment from others to highly anxious attachment, concerns over burdening others with problems, sensitivity to signs of abandonment or betrayal, and interpersonal conflicts arguments. As Jen described earlier in this chapter, she is always on the lookout for rejection.

Excessive or prolonged shaming can manifest in struggles with emotional regulation and create enduring problems in personal and intrapersonal interaction. As Janoff-Bulman (1992) notes, this can leave a person to feel very vulnerable and tend toward feeling 'on the spot' and unable to think clearly, speak freely, or take action in a situation. This can be seen in statements such as Bob's, 'I was unable to draw on myself'.

WHY THE BODY KEEPS SCORE

Next, I wish to explore how different regions of the brain are involved in processing emotional or physical threats. This is important because most of the research participants mentioned their physical responses to emotional Post Traumatic Stress. This could be understood to mean that physical trauma can have an emotional impact and emotional trauma can have a physical impact. The amygdala, for example, plays a crucial role in processing emotional stimuli and generating emotional responses, including fear (Dispensa, 2017). Meanwhile, the prefrontal cortex is involved in decision-making and assessing the potential consequences of actions, including those related to physical threats (Dispensa, 2017).

Despite differences in brain regions and processes, there is some overlap in the way the brain responds to emotional and physical threats. Both types of threats can activate the sympathetic nervous system, leading to physiological changes like increased heart rate, increased alertness, and heightened awareness. When you experience a threat, your body's sympathetic nervous system, often associated with the "fight or flight" response, is activated. This response prepares your body to respond to the potential danger. As part of this response, blood is redirected away from the digestive system and towards the muscles and organs needed for immediate action. This can lead to a feeling of discomfort or queasiness in the stomach because digestion is temporarily put on hold (Dispensa, 2017). As Jen says, 'Rejection is very much a visceral experience for me. It's in the pit of my stomach. Makes me feel like I'm gonna throw up'. Or as Sarah says, 'I feel that huge sense of feeling sick, panicked, headache, dazed'.

All participants seemed to have an awareness of the extreme pain of shame: 'I want the void to swallow me up whole, because that would be better than experiencing rejection' (Jen); '*I would rather just the ground swallow me or me just disappear rather than be in this experience*' (Sarah); and 'you'll want to cry, you'll want to melt into a puddle. You'll feel so ashamed' (Ziggy). I assert that we need to recognize shame as the number one reason people choose to end their lives. And we need to understand that shame is life threatening.

DISCONNECTION

Considering the huge threat 'shame' carries, 'dissociation' is a common response to experiencing trauma. Bob describes this as feeling, 'disconnected', 'separate', 'like it wasn't real.' Dissociation can include: (1) Becoming numb or dissociating from or suppressing one's emotions; (2) Avoiding thoughts or memories related to the trauma; and (3) Avoiding people, places, or activities that may trigger memories or emotions related to the trauma - leading to feelings of further isolation. Trauma withdrawal can have significant impacts on an individual's functioning - interfering with relationships, work, and daily activities. It can also lead to feelings of isolation, depression, and anxiety. As described by Bob, dissociation can be a protective response to trauma, allowing him to emotionally distance himself from the event. But it can also lead to a disconnection from himself and a lack of grounding in the present moment.

Classical dissociation theory (Lesley, 2016), for example, suggests that the person's ability to compartmentalize is a skill, is self-regulatory, and helps us prevent conscious awareness of the

trauma, especially if other resources are not available - such as finding protection or validation. Speaking to how multiple negative or threatening situations might impact a person Johnstone and Boyle offer the following:

A large part of the negative impact of these threats comes from factors that reinforce or make them worse. ... such as: the threats happen during childhood there is no one to support you, confide in or offer protection there are many kinds of threat the threats are long lasting, repeated and/or severe there is no clear way to avoid or escape the threatening situation ... threat(s) come from several sources (2018: 97).

CPTSD

Repeated acts of discrimination or discrimination coupled with invalidation can lead to complex PTSD (C-PTSD) (Livingston, 2019) which is a psychological condition that can develop in response to chronic or repeated trauma. Discrimination can be a particularly insidious form of trauma, as it can be subtle, pervasive, and ongoing. It can take many forms - such as acts which oppress and invalidate leading to a sense of being unable to find refuge. Afuape (2011) links the experience of repeated traumas to the experience of being a refugee who cannot find a safe place for themselves to be. I find this to be a very helpful comparison and draw further on this in order to gain more understanding of what someone with complex PTSD may experience. Papadopoulos (2002) divides the refugee experience into 4 stages: (1) *Anticipation*: the awareness that something hurtful will happen; (2) *Devastation*: Experiencing the traumatic event; (3) *Survival*: A retreat to isolation; and (4) *Adjustment*: Existing with the pain left from the experience. What Papadopoulos (2002) calls the Devastation stage and the Adjustment stage, reminds me of Jen's point about suffering the event and then living with the fact that you're someone that this has happened to.

Over time, repeated acts of discrimination can cause changes in the brain and the body that contribute to the development of C-PTSD. For example, ongoing stress and trauma can lead to dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis, which is involved in the stress response. This dysregulation can lead to changes in the levels of stress hormones, such as cortisol, which can impact mood, cognition, and physical health. (Dispensa, 2017). Ashok (2021) notes that this aligns with Bleuler's theory of a second illness. Many researchers have

argued this 'second illness', which is not an inherent aspect of one's cognition, is more disabling. I discuss the added effect of this developing in childhood in the next chapter.

To summarize, some of the symptoms of C-PTSD that may arise from discrimination include: (1) Hypervigilance: being constantly on guard and anticipating discrimination or harm; (2) Negative self-image: feeling shame, guilt, or self-blame as a result of experiencing discrimination; (3) Emotional dysregulation: experiencing intense or fluctuating emotions that are difficult to manage; (4) Avoidance: avoiding situations that may trigger memories or feelings related to discrimination; and (5) Difficulty trusting others: feeling sceptical or mistrusting of others as a result of having experienced discrimination.

For people who have suffered interpsychic trauma there is often an impairment in the ability to be self-referencing. This might come across as a person lacking a social spontaneity (i.e., not knowing what they want to do in social situations and therefore not instigating activities) or failing to facilitate connections with others. They may come across as 'easy-going' or a 'pushover' or 'boring'; indeed people suffering C-PTSD may not have started life with increased vulnerability but may have developed it. Self-stigmatization, also known as internalized oppression, is an act of self-protection - as to not embrace the external stigma would require living with awareness that the suffered rejection was unjust and cruel - along with often feeling powerless to change it. I propose internalizing stigma is a way of disassociating from the wrongness of the treatment received, but over time the internalized oppression becomes a permanent way of being. As Reeve (2011) comments this can result in different mental health problems and I would suggest this leads to repressed anger being turned into anxiety and other related conditions.

Pete Walker explains that the most common CPTSD traits include, "emotional flashbacks, toxic shame, self-abandonment, a vicious inner critic and social anxiety: (2018: 3 - 7). Internalized oppression, meaning self-policing acts, often go hand in hand with a loss of sense of self, self-stigma, and 'masking'. As heard from both Jen and Sarah- they experienced extended periods in their life where they lived in a state of hypervigilance. Jen referred to alternating between guilt and worry and uses the term 'exhaustion' to further describe the impact. Whereas Sarah describes her extreme efforts to feel good enough. These efforts might be understood as 'goal achieving' - a survival instinct in which the person (or animal) makes frantic attempts to secure

a better social position within the group which will offer them more security and likelihood of survival. For those who are facing the threat of feeling shame, survival might hinge on needing to feel valid as a person. This can often display as an attempt to be perfect.

MEANING: THE SELF IS BAD

On the other hand, many researchers would argue that it also works the other way around. Not only does trauma lead to feelings of self-blame or shame, but shame leads to feelings of having been traumatized.

To better understand this, the reader might think of a time they were extremely hurt by the actions of someone else. There will have been the immediate hurt in response to the action, and then often later there is the calling into question how having such an act done to you makes you seem to the other. For example, 'I must look so gullible to have been lied to like that' - or - 'What was it about me that made them think they could do that?'. The message being: 'There was something wrong with me that led to this act of abuse'.

Both Jen and Sarah reference self-blame. I come back to the technologies of self-blame. Jen and Sarah questioned what they were missing or if they were 'thick', a term used by both. Some of the key statements offered by Jen were, 'I feel ashamed for having been rejected. I should have done more. I should have done something different. I should have done better. I am worthless, I am a burden, I'm putting people out by merely existing'.

Researchers, Jennie Leskela, Michael Dieperink, and Paul Thuras (2011) have established that persons who have experienced trauma have a higher likelihood of developing shame. Reasons for this might include that the individual blames themselves for the traumatizing acts of others as a way of continuing to feel safe in the world (Leskela, 2002) so they create a rule which states, *I must have deserved that because people wouldn't be so unjust as to let me suffer undeservingly* (Gilbert, 2006).

In a way, this gives the victim of the trauma a sense of power over their ability to keep bad things from happening as they can strive to be better. Or this thinking at least keeps the world benevolent - even if they themselves must suffer. This links in with another theory proposed by Janoff-Bulman (1992) who asserts that trauma threatens three fundamental assumptions held in the survivor: "(1) that the world is benevolent, (2) that life is meaningful, and (3) that

the self is worthy” (cited in Finlay, 2012: 87). I note that beliefs (1) and (3) are about either the surrounding world or the self. I believe that for some, survival of the self hinges on deciding that the world is the untrustworthy place. Whereas for others, the survival strategy is to decide they are inherently flawed e.g. ‘the teacher treats me badly because I am bad’. For a child this is safer than, ‘the teacher and life are unfair and unpredictable’.

According to the PTMF, ‘I am at fault’ is a common meaning made by victims of mistreatment. This is demonstrated through Bob who made mistakes when his anxiety was getting the better of him and then felt ashamed for how this seemed to affect him more than it did his peers, and thus caused further feelings of inferiority and shame. Over time, people growing up as a minority within a culture that judges them as bad or less than will start to adopt the views of the majority, which at least to some degree, minimizes the reality of the unfairness (Becker 1963; Milton 2012).

SHAME

Jen’s excerpt is strikingly similar to Sarah’s in some of the phrasing regarding how she experienced shame when she says that *she would prefer to be swallowed, is afraid of being a burden and that these threats linger from childhood*. Like Bob, Jen describes being outside her window of tolerance, although Jen’s account is that she stays mentally present constantly aware of the possibility that she could reexperience the shame that was so ‘prevalent in formative years.’

Like Ziggy did in Chapter Seven, Sarah recounts multiple different environments in which she has received the messages of her badness.- which for her solidified her thinking that *she* was the problem. If we consider that shame is a trauma- an interpsychic wound- then what Sarah is describing is repeated acts of being traumatized, meaning that this would meet the criteria for compounded or complex trauma.

Like Bob, Sarah then describes her loss of connection - both with herself and others, ‘I had such a bad relationship with myself ... I felt really different from everyone else’.

SUICIDALITY

Eric Berne (1962) is credited with introducing the concept of 'Ok-ness' in Transactional Analysis, which suggests that every individual is inherently good and deserving. This concept was further developed by Frank Ernst who created the OK matrix or 'OK Corral'²⁷. These positions, also known as life positions', describe the different ways in which people perceive their connection to others.



Figure 9: The OK Corral

The position Sarah finds herself in is described as 'hopeless', which is regarded as a warning sign for suicidality amongst practitioners who uses Berne's model of transactional analysis. Although Sarah did not talk about ending her life, she spoke about the inescapable compounding shame she was living with, stating that she would rather 'the ground swallow her up'. I note that this word 'swallow' was the same she used to describe her taking in the messages that caused the shame. It is as if she has taken in this message of her badness so that eventually it would be less painful if it would consume her completely.

²⁷ Named after the infamous 1881 shootout in Tombstone, Arizona.

INTERNALIZING OPPRESSION / DOCILE BODIES

Boyle and Johnstone talk about the internalization of guilt and shame by victims who have not had a source of validation of their experience.

Less easy to identify but just as important is what is sometimes called self-surveillance and self-policing. This doesn't just mean being very aware of ourselves and how we behave. It means adopting the point of view of another person or group – sometimes known as an 'Other' – who represents the current cultural standards and expectations about behaviour, personal characteristics, desires and achievements. We then monitor ourselves and 'police' our own feelings and behaviour in line with these standards. However, we don't always realise we are doing this, especially when standards and expectations are very much taken for granted (2018: p.84).

In the case of all my participants, we see evidence that effects on their individual wellbeing do not simply remain in the temporal or geographical location in which the experience occurred. Often the participants spoke about being in states of extreme hypervigilance and worry about how others perceived them. This would tie in with Foucault's (1979) theory of being a 'docile body' which is self-policing and ready to comply with the aims of the institution or to social norms.

Similarly, 'internalized oppression' (Rosenwasser, 2002) refers to the process by which individuals from marginalized or oppressed groups come to accept and embody the stereotypes, biases, and norms of the dominant culture or society. They may begin to believe and internalize the negative messages and expectations placed on them, often resulting in self-doubt, self-censorship, and self-regulation to conform to societal norms and avoid discrimination.

Foucault's (1979) analysis of institutions and disciplinary practices reveals how individuals are subjected to various forms of regulation within institutions. This can include strict routines, hierarchical power structures, and mechanisms of control to ensure compliance. These disciplinary practices aim to create 'normal' subjects who adhere to societal norms and expectations. The constant normalization processes contribute to the production of 'docile

bodies' who willingly regulate their own behaviour to fit within the prescribed boundaries of acceptability. This can include adopting dominant cultural or institutional values and expectations, even if they are oppressive or discriminatory and have a negative impact on the individual's wellbeing or sense of self.

This self-regulation and internalized oppression serve to perpetuate existing power structures and inequalities, as individuals themselves participate in their own subjugation and the reinforcement of dominant norms. However, when an individual loses a sense of trust in their own perspective, that individual becomes vulnerable to conforming to the wishes of another person - whether the other person represents social norms or has any legitimate authority at all. In this way the individual may be vulnerable to antisocial acts of abuse and mistreatment. I do not believe this to be innate to autism, but rather the result of cultural conditioning, which has taught individuals they cannot trust themselves. By asking people to dismiss their sense of self to conform to cultural expectations we are diminishing their connection to their own moral or empathic compass.

Autistic adults are at increased risk for having had negative vulnerable life experiences (Griffiths et al., 2019). Recent research has indicated that up to 50% of autistic adults meet criteria for C-PTSD, with a further 11.2% meeting PTSD criteria, and that those meeting C-PTSD criteria had experienced more vulnerable life events and subsequently rated more highly on measures of autistic traits (Linden, 2023). It is therefore extremely important that trauma experiences and the resulting CPTSD symptoms are not inappropriately dismissed as a result of diagnostic overshadowing (Kern, 2007).

Of interest to me, was the difficulty I had with finding examples of internalized oppression from Ziggy's excerpts. In our interviews I experienced Ziggy as openly expressing more indignation than the other participants. I found his temperament relatable in a way that triggered my own insecurities about my tendency to be angry and 'stubborn'. I recognized that our presentations are less socially acceptable than self-deprecating expressions of anxiety or self-doubt. As I look back at the text, I see that Ziggy was doing something I consider brave; brave because it is often lonely and leads to more problems. He repeatedly rejected the right of others to diminish his own value. As he said, not being listened to caused 'major circuit breakers' which suggests that

if the other person wasn't trying to hear him properly and treat him with respect then the communication cycle simply stopped.

I am interested in how trauma can present as anger for some and anxiety for others. When thinking of trauma responses, anger is often seen to represent the fight response, as in the person is fighting to maintain a sense of self and a sense of self value. One of my neurodivergent clients used the term 'nerve damage' to describe the experience of being so frequently mistreated that one no longer feels the mistreatment. When someone can feel angry, even though it is painful and outside observers find it uncomfortable, it can lead to a breakdown that must be acknowledged. Of the fight response, Martin Luther King once said, "*A riot is the language of the unheard*" (1968). Although this presentation often puts a halt to the flow of the relationship that existed before, it allows the person or people to maintain a sense of self, rather than to abandon themselves to maintain the status quo.

CIRCUIT BREAKERS

Unlike Jen and Sarah, Ziggy starts with a position of evaluating the other person considering whether or not *he* will have a problem with *them*. He states the conditions under which he won't have a problem with them, but then specifies under what circumstances there would be 'major circuit failures' or total collapse. I hear these as other terms for 'disconnection' - which is the word Bob used. Loss of connection was a key theme for all participants, but here Ziggy is clear that he will enforce the disconnect: 'My hand will go in their face' and 'You won't hear any emotion from my voice'.

I did not think it was the scope of my study to judge wellbeing through an ability to maintain relationships or hold jobs, but it might also be worth noting that the other three participants seemed to have more success in these areas. Perhaps for them the communication cycle did not come to an abrupt end but continued on with the cost of constant worry of what the other was thinking, meaning that they were carrying more weight on their end of the communication cycle causing an imbalance in their lives. Balance or imbalance was decided to be the fundamental element of wellbeing in Chapter One of this thesis.

Minority groups have always had to contort themselves to fit in with the majority (Gardikiotis, 2011) in attempts to be smart, attractive and fit into stereotypes that current society finds

acceptable. Feminist theorist Laura Mulvey (1975) explored the concept of the 'male gaze', which describes the way in which girls and women are conditioned to view themselves from the perspective of men to be what I have conceptualised in this thesis as 'other-referencing' (Uher, 2023). They then adjust their behaviour and appearance accordingly, either to please or avoid displeasing men. Bob speaks about 'performance' when he states he feels pressure anytime he needs to 'perform or connect'. In one way or another, people in less powerful groups, due to age, class, ethnicity, sexuality or ability, often find themselves 'policing' their behaviour in line with the perspective of the dominant group (Eddo-Lodge, 2018; O'Grady, 2005).

What I take from this, is that anxiety and living in a state of hypervigilance leads to poor inner wellbeing, but it might be more palatable for others to be around as it relieves them of the effort required to listen and change. Ziggy states that if the other person doesn't do their part the communication cycle will stop. The breakdown may then get fixed or not, but either way Ziggy is not prepared to carry more on his end than he deems fair to himself.

With the total collapse of communication or the relationship, there is at least a chance that the other can decide if they are going to make changes needed to maintain the relationship. In situations where the wounded person keeps quiet, the strain may continue for some time without being acknowledged or remedied.

ABUSE WILL NOT BE TOLERATED

It is now May 2023, and many people are taking strike actions. Train drivers, postal workers, teachers and nurses, to name a few. In an article in *The Standard* I read about the nursing strikes some nurses articulated exactly what I am discussing here. They had this to say:

Patients and their relatives can sometimes be physically or verbally aggressive towards us because they are rightly scared and horrified about the setting, they are being treated in. Some are then arrested or removed by security (Roberts-Haslam, May 2023)

I was surprised to read these words which expressed an understanding for the reasonableness of the fear and anger and the injustice that is happening to patients. Such acknowledgment is

rarely voiced. I have seen it happen so many times that persons working with autistic people or their families, are taken aback by the distrust or resentment they have towards a system which has let them down and been dishonest repeatedly. Signs hang in GP waiting rooms which read, 'Abuse will not be tolerated'. Of course, it should not; but the problem is that they get to decide what 'abuse' is, and at times it may simply be a person trying to be heard and treated with respect which is then storied as 'abuse'. All that is seen is the person is 'difficult'. Massive societal injustices are left out of this story. The service recipient must then contend not just with mistreatments they have experienced, but increasingly the way they are viewed and spoken about by others. The trauma from past treatments is already present, but as the blame piles on top of that - oppression becomes the air they breathe.

SUMMARY

In this chapter participants use terms like 'snowball', 'tailspin', and 'circuit breakers' to illustrate the circular nature of self-understanding and communication exchanges along with the circular and erosive nature of intrapsychic trauma. This shows how early experiences of societal norms can deeply affect an individual's sense of self through the internalization of negative labels and recurring self-doubt. This effect is indicative of the long-lasting impact of power dynamics on an individual's well-being and the enduring nature of challenges of self-acceptance in the face of such powerful internalized discourses. It also acknowledges the role of trauma in shaping emotional responses to shame, rejection and acts of normalization. In Chapter Ten, participants start to discuss how they have broken this poor communication cycle.

CHAPTER 10: HEALING STRATEGIES

Language alone protects us from the scariness of things with no names

(Toni Morrison, December 7, 1993).

In Chapter Nine I looked at the meaning and survival strategies participants deployed after their experiences. I don't find a clear division between the meaning one makes, and the survival strategies they might deploy. The meaning and strategies for survival can be one in the same. Another way to understand this is that we shape our understanding of ourselves and the world in such a way that is the most conducive to our survival, even if doing so hurts. Feelings of shame are often a survival strategy.

Shame is held to mean the self is bad but *holding that belief* can also allow us to *survive* because we have accepted the thing that would harm us. This act of internalizing the shame then disempowers others who might apply shame onto us. It is a little like choosing to take the poison to build up a tolerance to; but, as I have shown in Chapter Nine, this can lead to an imbalance in one's long-term wellbeing because, like any survival instinct, this can become maladapted and become a habit which gets deployed at unhelpful, unnecessary times - shaping our lives into something which isn't a true expression of ourselves. We may avoid connection when connection would have been safe. We may berate ourselves when the other person wasn't going to. Or in situations where there has been offence we've caused, we may imagine the upset of the other to be much worse than what it was and we avoid repair because we can't conceive it is possible.

In this chapter I start to explore some of the healing strategies participants have chosen. I have identified these strategies as being those that have allowed participants to self-actualize and feel more balanced. I differentiate this from survival strategies, mostly seen in previous chapters, in which the participants often described feeling physically unwell or needing to take extreme actions to feel okay. I want to seek out healing strategies, not just to find a 'happy ending' for my participants, but more because of the contribution these accounts will have towards understanding what actions others might take to support the emotional well-being of autistic people.

BOB

In this section Bob is telling me about key moments in his life which have allowed him to develop a language and confidence about his ability to connect with others and make sense of his experience.

A WAY TO SAVE MYSELF

I don't know if I told you.
when I was in some young grade,
my aunt gave me a philosophy book,
Man's Search for Meaning
or something.

Everyone else is out playing,
but I was reading this big philosophy book,
it gave me a bigger world
than the smallness that I felt inside.

Philosophy taught me to articulate myself
writing a book,
I can take my time
formulate everything carefully
go back and change it,
but if I'm standing in front of somebody...
I can't draw on myself.

One thing I've always found
is that you do what you're passionate about,
you do what you love
and let it take you somewhere,

rather than trying to perform

you unfold in your way.

My first day at work,

as a crisis worker

I was terrified.

I thought,

because I had so much misunderstanding

and rejection in my life

I would be able to do it.

but I'll tell you,

I developed.

I just put myself in the place of, 'What would I need?'

I need someone to be there.

and present.

Not an expert,

not somebody perfect.

Just somebody to listen.

People found me a calming presence.

Helping other people

felt like a way I could rise above.

my own fears and challenges.

Being helpful just

felt like a way to save myself.

What I noticed from Bob's excerpt is that learning to articulate his own experience and become self-referencing was the key to him connecting more with others. In the first block, Bob tells us that his aunt gave him a philosophy book called *Man's Search for Meaning*. I find the fact that Bob found the exploration of meaning to be a thing which helped him shows how closely linked the act of meaning and healing are.

Man's Search for Meaning is a book by Victor E Frankl which chronicles his experiences as a prisoner in Nazi concentration camps during World War II. Frankl (1992) identifies a purpose to each person's life through one of three ways: the completion of tasks, caring for another person, or finding meaning by facing suffering with dignity.

Frankl's (1992) existential philosophy encompasses a deep exploration of one's cultural identity and heritage and emphasises the individual's capacity to rise above external circumstances and not be defined by stereotypes or prejudice. This concept can empower people who have experienced oppression to define their own identities and narratives, take responsibility for one's own life and overcome systemic barriers. It offers a framework for processing and healing from such trauma by finding meaning in one's personal and collective experiences.

When we hear or read of experiences of others which make sense to us, this is often a way of receiving validation ourselves because we are discovering that someone else in the world shares our experience and has given words to it. As discussed in previous chapters, not feeling validated compounds a sense of degradation from experienced traumas. Memoirs, psychology, and philosophy books in which human suffering is discussed often offer a sense of connection to the reader which would be de-othering. This is upheld by Bob's next statement, which is that it gave him 'a bigger world than the smallness' he felt.

Having read a book by someone else, in the next section Bob speaks about his process of writing his own book. He says he can take his time and formulate everything very carefully. This is a different experience to connection when standing in front of somebody. Writing offers him time and space to self-reference without worry of how the other person is seeing him. There is a safety in being able to articulate himself exactly as he wants without scrutiny from another until he is ready.

I consider that for a person who has experienced a lot of rejection and shame through interactions in his early years there would be a need for more time and space to get in touch with real feelings and experience, simply to know who they are.

In the third block Bob is talking about connecting with himself. He says that *when you do what you're passionate about, when you do what you love, you let it take you somewhere, instead of trying to perform*. First, I note that his experience is not about pleasing another person, but it's about doing the thing he loves. Bob then places this in contrast to trying to perform. I see this very much as a comparison to being self-referencing versus being other-referencing (Uher, 2023). When Bob says, 'let it take you somewhere', I feel this is almost a statement of being transcendental. To me, this is indicative of connecting with 'the source'. This might mean different things depending on a person's spiritual viewpoints; but to me, it seems as if it's taking Bob beyond himself - but, not to a specific other person. To me, it speaks to something bigger than the self as Bob said in the first block, 'You don't have to be okay with a specific other person. You don't have to perform. You can have your place within the world and be connected to the world at large'. For me this speaks to a very deep transcendent way of healing.

In the fourth block, Bob comes from the transcendental back to his surface level connections with others - this time as a crisis worker. And it takes him back into his anxiety. He said he was 'terrified' which he clearly links to experiences of being misunderstood and rejected. However, rather than his mind going blank and him not being able to draw on himself, Bob was more connected with himself. In the fifth block, he says he asked himself, 'What would I need?'. He then was able to draw upon that and offer that to the other person.

A discourse on autism, as previously discussed in this thesis, is that autistic people are not empathetic. What Bob is talking about here is that his journey towards empathy has been through being in touch with himself. This makes sense because empathy is about feeling what someone else is feeling and we can't do that without being in touch with our own feelings.

When Bob took some time away from being in the presence of another - going inside himself for reading and writing, and thinking about what he loved and letting that develop - he then became somebody who could offer connection and a calming presence to others.

In the last block, Bob says helping other people became a way he could rise above his fears. This shows the great power becoming self-referencing has to heal anxiety. Bob was given a space in which he could become more interested in *his* experience than worried about how others saw him - and in doing that, he learned to become self-referencing and intuitive about the needs of others – thus facilitating connections.

SARAH

Below, Sarah speaks about how negative messages from her childhood have stayed with her into adulthood and how she soothes herself when they come up for her.

I CAN SPEAK FOR MYSELF NOW

years ago, I would've just sat in shame.

while somebody told me I wasn't good enough

I didn't have any boundaries when I was younger.

I wasn't told anything about what was okay and what wasn't.

When I was a child.

I'd be so scared.

Now, through all the therapy

and the psychotherapy training I've had,

I do have more awareness of myself.

I can say...

“That wasn't my fault,

that the teacher shouted at me,

or threw my work,

or called me names.

I can leave that with her.

That wasn't my responsibility.

You're safe.

This isn't the same as back then.

You can take care of yourself now.

You can say how you feel”

As an adult I still feel that shame could come up,

but now I'll just say,

"I'm feeling really nervous.

This brings back memories of school.”

Usually, people are quite understanding.

I can speak for myself now.

In the first block, Sarah draws a link between not having been told what was and wasn't acceptable to her to not having the ability to set boundaries. This seems to me to suggest a need for validation in order to be self-referencing and help articulate her experience. But then validation (this came up with Bob) through therapy and psychotherapy training gives her more awareness. Therapy is often about offering a safe, non-judgmental space and unconditional positive regard (Rogers, 2012).

We know from Sarah's earlier experience that one of her therapists has wounded her with invalidation, but Sarah shared that she went on to see another therapist following the one she mentioned in Chapter Eight. Even in the one spoken about in Chapter Eight, Sarah obviously

felt enough self-awareness and trust to terminate the relationship. Although the relationship as a whole was not good enough for Sarah, having some space to explore her experience and sense of self was beneficial in that she was able to understand herself enough to know when she needed to leave. Psychotherapy training often (hopefully) carries with it an ethos of being a safe and compassionate space in which to be introspective, but it also offers many theoretical frameworks with which to articulate human experiences.

In block four, “In block four, Sarah recognizes the bad behavior of her teacher. The way she speaks about this, it sounds as though she has already processed her own hurt, and there is no longer a need for Sarah to be angry; instead the teacher’s behavior is identified as so wrong that it’s a burden belonging to that person. Sarah’s recourse is only to leave the teacher to carry the burden of her behavior.

I find this lack of need to punish or take action to rebalance denotes Sarah having reached a place – an internal balance - making this a positive survival strategy. Being able to connect with others and be vulnerable with others is a way of healing. Whilst Bob is expressing compassion towards others, Sarah talks about allowing it.

Jen

In the following Jen shares with us some of what has helped her to shift her thinking and how she has used her previous past experiences to empower herself and empower others. She identifies the things about her life which make her happy.

EXPLAINING OUR EXPERIENCE

what helped

was watching Hannah Gadsby.

An autistic and gay comedian.

she talks a lot about being diagnosed autistic and ADHD herself.

Says she was made to feel she wasn't worthy,

that her existence was
invalid.

That really resonated with me
and made me change

On the whole...

I am employed.

I am in a relationship.

I could be...

a recluse,

who doesn't get out of bed.

I don't let my past *define* me in that in that way.

Taking experiences and learning from them
and trying not to let the same thing happen to
anyone else

tends to be why

I consider myself advocate.

we hold far more compassion for others,
than we are given credit for.

Despite our experiences

we don't want others to feel that same way.

Jen starts by telling me about a comedian who is both autistic and gay. Jen finds watching Hannah Gadsby to be cathartic – it has landed with her in a deep emotional way. For Jen this experience of listening to somebody else talk about having gone through things that she has gone through has given her a sense of validation, which I note is counter to the feeling of being invalid or extremely different and unable to speak. It seems that Jen has found watching this comedian to be an extremely healing experience because she has been able to build a life that she has felt proud of.

Jen goes on to recognize the ways in which her life is working, noting that she is in a long-term relationship and in paid work. She takes the position that she has chosen not to let negative experiences from her past keep her from having these things in her life and that she has let her past inform on how she might be more supportive towards others, which gives another kind of meaning to her experience.

Like many of the participants, Jen finds that supporting others gives her a sense of positive self-identity. This identity is founded on discourses of compassion and challenging those in power while supporting marginalized individuals to find their own voice - something I note has been a journey both for Jen and for the other participants in my research. I feel that it's probably a hugely cathartic and healing experience to empower another person and support them in the way in which you yourself will have felt you wanted to be empowered.

ZIGGY

Here Ziggy tells us about a second appointment he has with a surgeon. This is a follow-on appointment from the original one which took place on the phone. We can recall that in that prior appointment Ziggy spoke about in Chapter Eight, Ziggy's doctor was not listening to his account of how he was feeling and what was going on with his knee. The following happened after lockdown had been eased - and Ziggy is now sat in a new appointment with a new surgeon.

MAGICALLY. JUST BY LOOKING.

I was passed over to Mr. Bolan

I knew with the tone,
he must've been informed.

I was:
awkward
difficult
a nightmare patient.

I cleared that up.
by just being myself
I was dead polite.
he changed immediately.

the way I address medical professionals now.

How best to put it ...

In their language,
in their words.

this isn't working.

It's causing major problems.

I tried to tell this to previous surgeon.

Now there's inflammation.

You seem like a rational person.

to be quite honest.

I am.

to be quite honest.

he looked at the metal sticking out of my knee,
protruding through my skin
all the way around my kneecap,
Then
magically
just by looking,
he came to the same conclusion.

The healing strategy I see being deployed here is one of perseverance and further attempts at articulating his experience: Ziggy carried on with trying to have the account of his pain taken seriously by a doctor. In thinking about the communication cycle, Ziggy is simply boundaried in how he expresses himself and continues on despite the first failed attempt. To make matters more complicated, he believes that the new surgeon he was speaking to was told that he was difficult. I find this extremely likely as such subjective opinions are often shared about service users, particularly if their reason for being transferred was to do with a breakdown in the relationship with the previous professional.

The act of perseverance was that Ziggy attempted again to articulate his experience for this new professional. Despite the early hint that the new surgeon had heard derogatory things about Ziggy, he did listen enough to consider the evidence before him - which was visual evidence of the metal protruding from Ziggy's kneecap! I note the previous surgeon spoke to Ziggy over phone.

Sometimes the information being discounted is simple and straightforward and the level to which the person suffering is being dismissed is simply hard to imagine. But it can be a problem when professionals enter into an exchange with a pre-judgment of the person they will

encounter. It can then be a further problem when they imagine that the person before them wouldn't have dismissed something so obvious. They then don't take the time to really look and consider for themselves. So, Ziggy kept making the effort, but part of the success of that survival strategy was dependent on finally encountering a doctor who was willing to make his own judgments.

DISCUSSION THEMES

Important themes I noticed from these sections were the experience of transformation often supported through the following: (1) Having a shared language or framework to help articulate one's experience; (2) Helping others. This seems to make positive use of difficult experiences. (3) Having time to go inward and reflect without pressure on one's own account of experiences; and (4) Being heard. Similar to theme two, this is about validation, but this is validation through the sharing of one's experience.

TRANSMUTATION OF SUBJECT POSITIONS

In Chapter Seven many participants shared early life experiences in which their life story was created by someone else. For example, Bob being treated like the class 'flea bag', Sarah being told she was 'thick', 'lazy' or 'dishonest', or as Ziggy put it, 'They were clearly more correct. Nobody could call them on anything'. When we consider how thoroughly their own narratives were taken over by others, it makes sense that the participants would seek out healing strategies that were about recreating their stories to transmute their understanding of what had transpired so that it can be congruent with their experience of self. I see this as a key to healing trauma which has resulted in a broken sense of self.

Klein (1952) offers the concept of 'transmuting internalization'. This refers to a psychological process in which an individual takes experiences and transforms them into their own psychological framework. Effectively, this is the act of renarrating or redeciding how to understand what has happened. This is often something that is done between two people, often in therapy, in which one person shares an experience they are ashamed of, and the other person normalizes or reexplains the situation. An example might be when an abuse victim is given a narrative that explains why they stayed or 'tolerated' acts of abuse. The act of being

able to understand and explain to oneself or others what has happened in a way that is acceptable to the individual is how we might transmute our sense of experience to ourselves.

Transmuting internalization can shape how the person perceives themselves, others, and the world around them. In the same way that choosing a subject position is not a conscious act, changing this often occurs at an unconscious level. Whilst much of this happens unconsciously, psychoanalytic therapy, like that based on the works of Klein (1952), often aims to bring these unconscious processes to conscious awareness, facilitating self-insight and emotional growth. Whilst this can be done with another person, I find that it can also happen with a book or piece of media in which someone is offering a framework that resonates with the listener. Just like Jen found Hannah Gadsby (2020) caused her thinking to shift. Or for Bob, Victor Frankl (1992) was inspiring.

To change a subject position within a Foucauldian framework (1982), one would need to engage in a process of critical self-examination and deconstruction of the existing discourses and power relations that have shaped their identity. This might involve questioning the dominant narratives and categories that have defined who they are and striving to break free from these limiting constraints. It could also involve reappropriating or redefining one's identity in ways that challenge the normative or oppressive structures that have been in place.

During the internalization process, the individual absorbs, or 'internalizes' these new narratives, often unconsciously. This means that the emotions, perceptions and interpersonal dynamics associated with these experiences become part of the individual's inner world and psychological makeup.

Transmuting internalization not only helps individuals understand their own emotions but also enhances their ability to communicate with others. In her PhD dissertation, Debra Leven (2020) explored what factors went into the decision to disclose an autism diagnosis at work. Leven did a narrative analysis of interviews with 10 autistic adults. One of the subthemes that emerged in Leven's research was the individual's past experiences with seeking support from school and other professional agencies. These experiences had a notable influence on whether or not the person felt safe disclosing their condition and requesting support, or whether they felt the

need to hide their condition and try to manage without understanding from others. As Leven notes:

Furthermore, it's important to acknowledge the impact of stigma on the behaviours of autistic individuals who may engage in camouflaging their autistic traits as a way to conform and be accepted by neurotypical society. This desire to 'fit in' often arises due to the social stigma and discrimination faced by autistic individuals.' (2020: 132-133)

Both Klein (1952) and Foucault (1982) believe we need to be aware of how discourses affect our sense of self and suggest these are subject positions that can be transformed through a critical analysis of dominant discourses and power dynamics, and a willingness to challenge and reshape them.

LANGUAGE

Language in itself is powerful as it not only helps us to process and organize our experiences, but also the fact that it offers words to describe our experiences and lets us know we are not alone in the world: What we're feeling, thinking and experiencing – has a name.

Something I heard from all the participants is how they have used language to help themselves. For the most part the language I am referring to is philosophy or psychology, but it might be any terminology which helps the person express themselves to others. Sarah talked about how her therapy training offered her a language through which to express herself. When you can articulate your feelings effectively, it improves your ability to express yourself to loved ones, friends, or mental health professionals, facilitating more meaningful and supportive relationships. As an example of this, Sarah would simply let people around her know when she was being reminded of trauma from school.

It seems that Sarah also used the knowledge gained through her training as a foundation for long-term emotional resilience. As individuals become more adept at understanding and processing their emotions, they are better equipped to handle future challenges and stressors. It is through this language, theory, and ability to understand ourselves that healing starts to occur, and confidence can grow.

Bob spoke about the transformation he experienced in his adolescence when he started reading. Books can offer language and concepts to make sense of complex emotional experiences. I believe that having terminologies to articulate our experiences helps them to be less shaming.

When individuals learn that their emotional experiences are not unique, that others have also felt the same way, it brings a sense of normalization. Reflecting on your life and experiences can lead to a greater appreciation of the positive aspects, which can help you approach your relationships with a more grateful and positive attitude. Expressing gratitude in your interactions with others can strengthen your connections and contribute to your overall well-being. Bob said that a philosophy book offered him a bigger world than the smallness in his head. This reassures individuals that their feelings are valid and part of the human condition, hence this offers a sense of connection rather than the otherness they might be feeling. It allows also a framework through which to navigate oppression.

Psychoeducation helps people identify healthy coping strategies, setting them on a path to emotional well-being. I find that the topic of coping strategies and life choices tend towards behaviour-based assessments; but I don't try to completely avoid assessments of behaviours, particularly when the person is assessing their own behaviour as Jen has done when she states that she is in a long-term relationship and employment. Whilst this is not a statement about inner-experience, I understand Jen's assessment of herself to be that she has done inner psychic work in order to have these practical aspects of her life be as she wants them to be.

SELF-REFLECTION

Bob spoke about staying inside to read the philosophy book his aunt gave him when other children were out playing. Bob also referred to writing as a way to express himself because in writing he could go back and edit. This suggests there was an act of reflection going on as he expressed himself. If I think about the communication cycle in which we say something and wait for a response, part of Bob's trauma occurred in the understanding aspect of this. For Bob, writing was an opportunity to say what he wanted. To sit with it. And to amend any statements so that they reflected his most authentic truth. Essentially, writing is, for many, a tool we use to process our feelings rather than seeking feedback from others.

Self-reflection often includes considering your own experiences and emotions in relation to those of others. This practice can lead to increased empathy as you become more attuned to the emotions and perspectives of others. When he was starting work as a counsellor, Bob said that he asked himself what he would need. In this act of self-referencing he was able to identify what he needed most was someone to be present.

Self-reflection allows us to establish and maintain healthy boundaries in our relationships. Understanding our own needs, limits, and values allows us to communicate our boundaries clearly to others. This fosters respect and trust in our interactions. Sarah has spoken about her development of boundaries in her training and her personal therapy. Both of these experiences will have offered her a space to be self-reflective.

Self-reflection can improve problem-solving abilities by helping people to analyze situations more objectively. This analytical mindset can be valuable when addressing interpersonal challenges and seeking solutions that benefit all parties involved. As Jen has said, she used her experience to inform her understanding of herself and others to make her life what she wanted it to be, as much as she could.

VALIDATION

Trauma researcher and writer Don Cathedral states:

A common effect of individual traumatization is that the survivor grows increasingly distrustful of his or her own perceptions, emotions, and judgment. Trauma survivors typically need greater validation from others - they need to know whether what they are feeling and perceiving makes sense to other people, or whether there is something defective in their mental processes (2012: 461).

Bob's wife seems to offer him a sense of safety from painful disapproval, but at the same time he is still holding a 'deep fear' that he could still see the 'what were you thinking' look. A look which I would guess we all see from time to time, even in the faces of those we love most. It may be that for Bob, his relationship with his wife is a 'good enough' relationship in which he gets more healing validation than retraumatizing disapproval, which allows him to repair his inner sense of self.

Janoff-Bulman (1992) tells us that the validation received from significant others will play a crucial role in the mental wellbeing of those living with post-traumatic stress. Although in Bob's case the significant other is Bob's wife - which tends to be in-line with the traditional understanding of the term 'significant other' - non-romantic relationships are also often significant to us and carry great weight.

Being validated by another person is a powerful interpersonal dynamic that can have a significant impact on one's confidence in their ability to connect with others. For Jen, listening to Hannah Gadsby made her feel understood and less alone. This is a form of validation. When someone validates your thoughts, feelings, or experiences, it helps you accept yourself more fully. It sends the message that your emotions and perspectives are normal and understood. Validation provides emotional support which is crucial for mental and emotional well-being. It communicates that your emotions matter and that you are not alone in your feelings. This support can boost your emotional resilience and make it easier to cope with life's challenges. Validation can encourage self-reflection. When someone acknowledges your feelings or experiences, it prompts you to explore and understand your own emotions better. This process of self-awareness can lead to personal growth and increased insight into your own thoughts and behaviours and it fosters a sense of mutual understanding and trust in your relationships. When you validate others and they validate you in return, it strengthens the bond between you. When feelings of inability to connect start to heal the individual may start to feel brave and try again to forge connections with others. This is illustrated through Bob's account of entering into a career as a counsellor: he was able to draw upon himself and consider what it was he would need. This requires a sense of self trust, which is precisely what he needed to heal.

A seemingly apt response to this would be narrative therapy, which was developed in the 1980s by two psychologists from New Zealand named Michael White and David Epston (Payne, 2006). The aim of narrative therapy is to explore the narratives that individuals hold about themselves and reconsider them. By doing this the individual might begin to separate how they have been storied or treated by others from their identities. This means seeing their past as something outside of themselves, rather than as inherent aspects of who they are. Whilst narrative therapy may be used by therapists, the principles can be implemented by anyone, in which the listener offers validation and asks non-leading questions which offers the speaker a space to

consider the story they feel most truly represents their experience. It is important to validate the speaker and not reinforce power structures that marginalize.

HELPING OTHERS

Another shared theme I have noticed is that three of the four participants have sought careers that involve helping others. Although I fully believe the desire to alleviate suffering in others is a genuine felt sense, I believe this is a safe way of experiencing connections with others. Both Bob and Jen expressed a sense of confidence about what others would need. Bob recognized there was no need to be an 'expert' but rather to simply be present with the other person. Interestingly, whilst this sounds like it should take the pressure off, many young therapists I supervise find the act of simply being present without offering answers anxiety inducing. The reality, which Bob knew already through his own life experience, is that others rarely have the answers. People need to find their own understanding and simply want emotional support as they explore. Having lived through the experience of wanting exactly this, Bob was uniquely skilled to potentially offer this to others. In the same way that the communication cycle is dependent on the confidence of the speaker that the message is received and felt by the other, so is the confidence of the listener that they are conveying their genuine interest in what they are being told.

For many, acts of witnessing, listening or advocating can boost one's own self esteem as the helper is able to feel confident in their ability to understand another and be valued for this skill set. For many, these careers become a calling, giving one a sense of purpose in life. This ties into the book Bob was reading about the meaning man makes of life. It also ties into Bob's phrase that the book gave him a sense of something bigger than the smallness he felt inside. I believe the same extends to connectedness, empathy and support. When you focus on someone else's needs or problems, it can divert your attention from your own worries and stressors. When we recognize the strife of others, it forces us to see beyond just ourselves.

Personally, I have found the recognition of human suffering to be more deeply depressing as I realize the traumas I have suffered are not unique and not even so bad compared to the suffering others have experienced. That so many people suffer so much is depressing and can take one's mind through a warren of darkness, but at the other end there is transformation. I am always brought back to the realization that the foundation of suffering is a universal longing

for connection. The cruelty and ignorance, although responsible for much of the suffering, is only static. It is only covering a constant longing for connection. Bob, Jen and Sarah sought out careers in which they could offer themselves to others in search of connection. As Jen says - *we don't want others to suffer in the same way we have*. I believe in the same way that there is a circular nature to communication: offering empathy to others leads to more self-compassion as we can stand outside a person and often look more objectively at them than we do ourselves.

By helping others, some of my research participants gained a better understanding of their needs, feelings, and struggles. This enhanced empathy led to a broader perspective on their challenges and a more compassionate approach to self-reflection. Lastly all participants spoke about a lack of agency in their early lives. Helping others allowed them to reclaim this agency and counterbalance feelings of helplessness.

SUMMARY

In this chapter participants spoke about the role therapy and philosophy played in helping them to reclaim a self that was suppressed through previous experiences within institutions throughout their lives. It also showed how they used advocacy and compassion to further solidify their sense of self. It also offers evidence that through personal resilience we can challenge current discourses to find understanding and recognition. In the next chapter I will bring together the main messages of all previous chapters, creating some semblance of an answer to my research question.

CHAPTER 11: THE TRAUMA OF NORMATIVE BIAS

Research question:

'How is the long-term wellbeing of autistic adults affected by the experience of ethnocentric judgments from non-autistics professionals within education, health, and social services?

In Chapters Seven through Ten, I have worked with my participants' stories to show how experiences of ethnocentric judgments from professional helpers have affected their sense of self and safety in the world. In Chapters Seven and Eight the stories focused on the judgments and treatments the participants experienced throughout school and into their adult lives. My analysis of these chapters looked at who had the power to decide what was true, the subjectification process, and the battle for self-identity. Chapter Nine looked at the internalized meaning the research participants made and carried from the judgments and treatments they received. Chapter Ten looked at what steps the participants took to connect with themselves and feel safe with others. These four chapters together demonstrate a sense of how harm was done, the predictable nature of this harm and what has been found helpful in the healing process.

JUDGMENTS AND TREATMENTS

The participants shared stories of being held responsible and frequently criticized for their differences. By framing these differences as problems created by the individual the institutions were able to function without making substantial changes. While this approach may be pragmatic for the institution, it comes at the expense of the long-term well-being of the individual.

In Chapter Nine I focused on the participants' comprehension of their experiences, and how these affected them and I found that, based on the stories shared, threats to self-identity during childhood can have a lasting impact on a person's identity development and that this correlated with the research I referenced in Chapter Six. Interpsychic trauma can lead to self-stigmatization, internalized oppression, and other mental health problems. Understanding the interplay between trauma, shame, and self-blame can help individuals navigate the complex and often challenging experiences of C-PTSD. William Fairbairn's (2013) 'moral defence' theory

suggests that children may feel bad about themselves instead of accepting the unfair world they live in, leading to self-stigma. Shame is often experienced as a response to disconnect, leading to feelings of isolation and depression.

As an example of this, Sarah spoke about self-doubt, stating that as a child she 'swallowed whole' an understanding that she was bad at writing stories or that she was 'lazy.' Both Jen and Sarah call into question their intelligence, whereas Ziggy was pushing back by clarifying that he was 'in no way an idiot'. But for all of them there was an awareness that their perspective and rationale was being judged as wrong. To understand the participant's responses as self-doubt doesn't fully do them justice. One's whole sense of self is diminished when they have experienced repeated contradictions or rejections of their inner experience. This is evidenced by Bob and Sarah's ongoing struggle to define their identities and by Jen, who didn't share early childhood accounts, but shared her struggles in finding a firm footing in her sense of legitimacy.

As adults, each of the four participants expressed a strong awareness of the 'look' they might receive from others. This 'look' can be understood as the first step towards connection or disconnection with another person. For Sarah, Bob, and Jen, there was a visceral fear of what might be communicated in this 'look'. In contrast, Ziggy exhibited a readiness to set protective boundaries at the first sign of Othering. For me, it was Bob's fear and avoidance of seeing the look on someone's face when they simply didn't share his experience at all, that resonated most deeply. All four indicated a hyper-awareness of connection or rejections. This hyper awareness of possible rejection to me suggest a trauma response to rejection demonstrating that rejection and othering can be experienced as a trauma.

As adults, Bob and Sarah embarked on a journey to name their differences, only to encounter rejection. Ziggy and Jen also had narratives of not being understood or listened to by others in their adult lives. A common thread through these experiences was that those who chose not to listen held significant power and influence in the lives of my research participants as they faced ethnocentric judgments- ranging from moral condemnation to perceived incapability and the outright dismissal of their perspectives.

Sarah, Bob, and Jen also shared elements of what they did to promote self-healing, while Ziggy offered a story of perseverance as he remained true to himself and continued to offer his accounts to others. All of them provided valuable insights into the long-term effects of ethnocentric judgments and the importance of being seen and understood appropriately by professional helpers.

HOW A DISCONNECT FROM THE SELF CAUSES A DISCONNECT FROM OTHERS

As I wrote at the beginning of this thesis, ‘understanding’ was the key theme to emerge from my MSc research. My MSc participants expressed a need for self-understanding, understanding from others, and an anticipation about whether or not they would be understood. I was only just starting to see it back then, but all of this was about the relationships between themselves and others.

In Chapter One I make the point that all experiences, whether good or bad, create imprints in our nervous systems and are remembered in our bodies. These imprints condition us to anticipate more of what we have already experienced. This mechanism enables us to learn tasks, develop anticipation for things we enjoy, and even develop anticipation for things we fear. Essentially, the same mechanisms that enable learning in general shape our understanding of all aspects of the world. Jen echoed a similar point in Chapter Nine and Afuape's (2011) argument is that repeated experiences will have a *more* deeply ingrained impact than intense one-off events. Keeping this in mind, it becomes clear why my research participants have had the deep long term impacts they have, due to living amid everyday social expectations and discourses that run counter to who they are. These consequences stem more from the erosion of their sense of self than from the naturally occurring divergence of their neurological wiring. Stepping back from the research, a primary observation is that such experiences diminish one's sense of self and their ability to form connections with others as themselves. The less connected we are with ourselves, the less we can be connected to others. This, in turn, has ripple effects that cause difficulties within professional and personal relationships. For example, it created challenges for Bob in job applications and hindered Jen's ability to communicate effectively with her manager. While three of the four had romantic partners and two had satisfying careers, all of them shared stories of the barriers they had to overcome, barriers that need not have been there in the first place.

Two of the participants referred to circuitry in their communication and in their sense of self. I think circuits are a good metaphor for this. As the communication process seems to happen instantaneously, it might be helpful to slow down the process, unpick it and understand what steps are happening and where the breakdown might be happening. Below I have created a list of steps which unpicks the communication process.

INTERNAL PROCESS

1. Person 1 has an experience.
2. Person 1 can name and understand their experience as valid.
3. Person 1 expects that other people will be able to understand and believe their experience.

EXTERNAL EXPRESSION

4. Person 1 speaks to the other about their experience.

CONNECTION RECEIVED

5. Person 2 can see that Person 1's experience is real for them and they expect to be heard and understood.
6. Person 2 hears and understands them.

CONNECTION RETURNED

7. Person 2 offers confirmation to Person 1 that they have been heard.

Looking at an article on the Bax Music website about balanced and unbalanced connections between stereo cables I found the following passage:

For a balanced connection, both linked devices need to have a balanced socket (sense of self). This ensures that the emitted signal is duplicated: one is sent normally, and a copy is sent with reversed polarity (April 2023).

If the feedback a person receives is out of alignment with what they have felt about themselves, they may learn they can't know themselves. Alternatively, they may learn that they are not likely to be heard or understood. In either case the communication cycle starts to break down. Both Sarah and Bob spoke of experiences of feeling misunderstood in their primary schools. Sarah was labelled 'daft'. Even when she told the teacher how she had come to complete

certain assignments the teacher would respond by stating that Sarah had been dishonest. Bob became the class flea bag and both him and Sarah struggled as adults to be heard and validated by those they spoke to about their perceived autism. Ziggy on the other hand was more general in terms of stating, 'They were right I was wrong', whereas Jen's sense of being misunderstood was transmitted in the silence of looks. Ziggy describes the efforts he went to be understood more clearly by learning to speak to medical staff in their language and Jen describes the importance of feedback from the listener as she states she needs someone to respond with an indication that 'they get it' which comes back to Bob's statement that he could see from the look on someone's face that they didn't understand his experience at all.

WHY DISCONNECTION FROM THE SELF AND OTHERS IS A TRAUMA

If we understand the word 'trauma' to mean something which has been broken, then we could say that a physical wound is always a physical trauma. Anyone who has broken their leg has suffered a physical trauma. Therefore, anyone who has experienced a break in their sense of self or their ability to have a clear attachment with others has suffered a psychological trauma "at least in part to suffering from an incoherent story or an inadequate narrative account of oneself" (Foucault, 1982: 452). Leslie (2016) notes that Foucault, Lemke, Janet, Breuer, Freud and Broucek all seem to be in agreement that a rupture in one's sense of reality (the 'singular experience') is a trauma. Pierre Janet (2016), who wrote the first book on PTSD referred to this split in realities as 'dissociation'. Joseph Breuer and Sigmund Freud (1893) called it 'double consciousness'. Arthur Frank (1995) uses the term 'narrative wreckage'.

According to shame researcher and psychotherapist Patricia DeYoung (2015), personal well-being depends on a sense of an integrated self and to not have this cohesion between self and discourse threatens psychological annihilation' (DeYoung: 19) If we consider for a moment the gravity of this statement - DeYoung is writing about a threat of obliteration of the self. Her word choice, 'annihilation' reminds me of some of the words my participants used when describing their experience such as 'void'. I hold in mind that both Sarah and Jen made statements to the effect that they would rather not exist than to continue in a state of shame.

In my view, this makes experiences of large-scale acts of being misunderstood, dismissed or mis-storied *very likely* to cause trauma. This is unique in that very few life events can be said to predictably cause trauma. In most cases there is not a set experience that will always equate

to a trauma for every person. A car accident, a violent crime, a natural disaster may all traumatize one person and not another. But in the case of institutional ‘narrative wreckage’ (1995), the damage is consistent and predictable. And it seems lessons, have not yet been learned.

In Chapter Four I wrote about a young woman named Zoe, who had taken her own life after discovering what had been written in her medical records. Before her death Zoe posted the following on Twitter:

“I feel trapped in a living nightmare.

they have taken my hope and identity from me,

I don’t want to be part of it,

I just want to die”.

Her mother was quoted as saying: ‘They had turned her into someone she was not’²⁸.

RECONNECTING

My participants often shared early life experiences where their narratives were created by someone else, leading to trouble with self-identity. It seems that, because language played a pivotal role both in having an identity applied to them, it would also play a key role in understanding and expressing their own experience. As I noted earlier in this thesis, Melanie Klein emphasizes the importance of early interpersonal relationships and the development of a secure self-concept and she proposes the concept of ‘transmuting internalization’ which suggests that individuals can transform experiences into their own psychological framework through therapy or re-examination. Similarly, in a Foucauldian framework, changing a

²⁸ www.Darlingtonandstocktontimes.com, April 2022

subject position involves critical self-examination and the deconstruction of dominant discourses and power relations.

Jen, Sarah and Bob all sought careers that involve understanding the human experience. Jen went into social work and writing. Bob went into counselling and writing. Sarah became a psychotherapist. Ziggy did not go into these fields, but he was the one who seemed to have remained aware of the conflict between his experience and the perceptions of those in power.

Foucault's (1982) work on power, knowledge, and discourse can be interpreted in a way that sheds light on how subject positions can be transformed or challenged. Foucault's (1982) ideas on the relationship between power, knowledge, and subjectivity suggest that subject positions are not fixed or essential but are instead constructed through social and discursive practices as he argues that power is not just a force that represses or limits individuals: it also plays a role in constituting and shaping subjects as seen with Bob's 5th grade teacher whom he attributed to his transformation from loser to achiever; and Sarah's English teacher - whom she credits with encouraging her to go to university. These are only two examples of transformation. Others can be seen – such as the sense of validation Jen got for Hannah Gadsby's philosophy book for Bob. This shows us that subject positions do not need to be fixed, but rather emerge from the interplay of various power structures and knowledge systems.

CONCLUSION

Here, in this research I find that understanding was also the key theme, but it became clear that for most, it was *self*-understanding and the anticipation of being understood, where the breakdowns were occurring.

Using Barnes' (2016) definition of wellbeing, which I discussed in Chapter One as a sense of balance, I combed through the lyrical transcriptions looking for phrases that indicated a sense of imbalance. I have extracted some of the phrases I found (there were others) which I felt best highlighted imbalance. The overall message that I took was that the imbalance experienced was a sense of valuing others more than the self. This may sound like a kind or morally good personality trait, but over time this can cause an individual to: (1) lose self-awareness; (2) question their perception of reality; and (3) be vulnerable to the wants and agendas of others regardless of whether it's harmful. If we imagine the connection-cycle like a tube with energy

flowing through it, then we might see the imbalance as a stuckness in which one area does not flow freely and thus becomes heavy or blocked.

IMBALANCE

they were right-I was wrong.

I was too anxious. Too disconnected.

It just caused **more and more collapse on myself**

I was constantly on tenterhooks.

It is absolutely exhausting.

I will have a strong feeling of not being okay,

I still have this deep fear that I'm wrong.

there must be something wrong with me.

I am worth less.

In the earliest literature, autistic children were described as “withdrawn and disconnected” (Manouilenko, 2015: 17). This can be seen in Bob’s description of himself. Another description is that the person is “highly focussed on their own interest” (Manouilenko, 2015: 17). This might be demonstrated in Sarah, Jen or Ziggy’s efforts to master their chosen topics to ensure acceptance. Frith and Happé, write that autism, “is a devastating disorder because it [autism] disrupts not only understanding of others and social relationships, but also understanding of the self” (1999: 18). What is not said in in this quote from Frith and Happé is that autistic self-understanding is being evaluated through a neurotypical lens. What is also unsaid is that Frith and Happé are writing about a group of people who have likely had their inner experience invalidated throughout their lives. What is unseen and unacknowledged is that a lack of self-awareness may not be the product of a person having autism but of growing up with a lack of mirroring and attunement during their developmental years.

Blogger Ann Memmott writes:

If you spend decades telling an autistic person that they have no idea what their needs are...that they aren't really communicating...that their behaviour doesn't mean what they think it means...that the things that they need are not needed.... that they are mistaken about what's happened to them... then we do end up thinking we've totally 'lost the plot'. People so often remove our entire reality and replace it with their own version of it. (Autism: Denials and 'Gaslighting', 17 December 2015)

I long understood that my participants were speaking about a breakdown in self-understanding, but only towards the end of my study have I started to see a pattern of how the breakdown of self-understanding led to a continuation of not being understood throughout one's life. Below I share a passage that I read on Facebook by NeuroWild as she writes about the struggle this has caused for her:

It's absolutely essential that our neurodivergent kids grow up into teens and adults who are able to speak up for themselves when they need to.

I have never been able to do it.

I haven't been able to express slight disagreement in a casual setting. I haven't been able to tell someone they aren't allowed to stand that close to me or put their hand on me. I don't know how to tell someone that their behaviour and words are inappropriate towards me. I don't know how to draw a boundary or tell someone no.

Instead of developing these essential skills, I learned uncontrollable people-pleasing. How did that happen? I was rewarded for fawning. I was praised when I ignored my own needs. I was praised when I kept the peace. I was praised for not getting upset in response to people. I was praised for being so good.

It was so damaging (March 28, 2023).

SUMMARY

The main thing I've learned from conducting this study is that the individual's sense of self, self-identity and self-worth are circular. We are, from early life, sent messages from others around us about who we are and how we are valued. And then, throughout the rest of our lives, we relay those messages to everyone we meet. If we were told we were lazy, hard to understand, dishonest or disabled, we continue to express a sense of this to others. We either play the part or go desperately in the other direction attempting to convince someone not to see us this way. When we expect a certain response from another based on how we have been treated in the past this is called 'transference' (Freud, 1977). But when we attempt to avoid a repeat of past experiences, this can be counterproductive and the other will perceive our attempts to 'overcorrect' as another message that something is wrong with us - 'why are you trying to convince me you're telling the truth - you must be lying'. This response is called *countertransference* (Freud, 1977). People who meet us throughout our lives take us on what seems to be our own estimate of self. This then goes on to affect most areas of our life. In this study the participants recounted instances when some of the professionals in their lives failed to listen, understand, or take them seriously. I found that these stories offered personal illustrations of the intricate connection between privilege and power within the lives of those with ASC, particularly in authoritative professions and the enduring impact childhood experiences can have on an individual's ability to advocate for themselves. My hope is that these stories gave life to and made understandable the circular nature of how we as people develop.

PART FOUR: CONCLUDING THOUGHTS

Chapter 12: HOW TO *NOT* TRAUMATIZE AUTISTIC PEOPLE

GUIDELINES FOR CARING PROFESSIONALS

Be forthcoming with your own vulnerability and use language that equalises you in the people around, you speak intentionally to humble yourself and build trust. Leadership is a Relationship (Erwin, 2022: page number)

In my research I have drawn from my personal experience, my work as a psychotherapist, and the stories generously shared by my research participants. Here in this chapter, I start addressing the reader directly as a practitioner as I pull primarily from the participant's stories to create good practice guidelines practitioners can use when working with autistic people and their families. These findings are written in a list format for ease of reference.

This chapter will be divided into four main themes: (1) Looking after yourself - in this section we explore the importance of self-care to create a resilient foundation upon which you can draw to better support those we serve; (2) Critical thinking - here we look at how we might identify problematic discourses and question narratives which might mis-narrate autistic individuals and their families; (3) Supporting others to become self-referencing - here I explore how we might enable others to better connect with themselves; and (4) De-othering - this final section explores the how we might further help someone to heal from the pain of having been othered.

1. NURTURE WELL-BEING TO COMBAT BURNOUT

She grabbed me by the ear.

The more I tried to tell him the more he got his
back up.

She shouted at me.

It's like a circuit breaker, it's not that we don't care.

We shut off to avoid a meltdown.

In the contemporary society of the Western world, where individuals often describe themselves as 'cogs in a machine' or 'circuit breakers,' it is crucial to recognize the dual nature of our existence within institutions where we are interconnected yet individual parts. Burnout,

a pervasive challenge, doesn't discriminate, affecting not only those on the autism spectrum but anyone engaged in 'emotional labor' (Hochschild, 1983). As we navigate the demands of the workplace, it becomes imperative to prioritize our mental and emotional health.

The term 'burnout,' coined by Herbert Freudenberger (1974), vividly encapsulates the exhaustion experienced in our daily work. Additionally, Carla Joinson (1992) introduced 'compassion fatigue', highlighting the emergence of apathy among individuals in helping professions. As caring professionals, we must guard against growing indifferent to the well-being of those we are meant to care for, a phenomenon closely related to the focus of this directive.

In environments lacking critical thought and empathy, biases tend to thrive, often found in harsh working conditions, especially in public sectors. Caring professionals depend on empathy and compassion, but like any finite resource, these qualities require rest and recovery to be sustained. It is essential to acknowledge that our ability to respect and empathize with others cannot be mechanically taught; it necessitates emotional availability and connection.

The prevailing emphasis on constant productivity in our society has a detrimental effect on compassion and empathy for all, irrespective of neurodiversity. Institutions, driven by capitalist agendas, risk suppressing the very essence of what makes us human: our innate ability to empathize and care for one another.

To counteract these challenges and foster a healthier professional environment, I believe it is important for practitioners to:

1. Choose a workplace that genuinely values well-being.
2. Set boundaries and resist excessive demands that can lead to burnout.
3. Take time for self-reflection.
4. Consider if training and directives align with a trauma-informed approach as outlined in this thesis, ensuring alignment with your values.
5. Recognize that empathy cannot be mechanically taught.
6. Create space within yourself to genuinely feel and connect with others.
7. Advocate for a balanced approach that values human connection over relentless productivity.

8. Be vigilant against growing indifferent to the well-being of those you care for. Regularly assess and address signs of compassion fatigue.

It is important to remember, the ultimate form of self-care involves deliberate choices that prioritize your well-being, foster genuine connections, and create a workplace environment that values the essence of our shared humanity.

2. CHECK YOUR PRIVILEGE

he just blatantly shut me down several times.

you have to accept yourself.

You won't be able to be a therapist and be autistic.

****Directive for Cultivating Awareness of Power and Privilege in Professional Interactions****

My research participants illuminated instances where they felt judged, silenced, or mis-storied by those in power who lacked an understanding of their lived experiences. Recognizing such dynamics is crucial for fostering an inclusive and supportive environment. [When those in power are oblivious to the effect their power can have on the other this is termed privilege.](#) Privilege, as Afuape (2011) points out, is not necessarily intentional harm or malicious intent, but harm done through a lack of understanding and unwillingness to listen.

Understanding and addressing privilege is a multifaceted process. To do this it is important to:

- a. Acknowledge and reflect on your own privileges. These may include aspects such as physical appearance, cultural alignment, and educational opportunities.
- b. Privilege is not inherently fair. Recognize that privilege can vary across environments and contexts. What may be considered a privilege in one setting might change in another.
- c. Be attuned to the fluid nature of privilege and power. Understand that individuals hold multiple identities, and privilege can intersect and overlap.

- d. Acknowledge the complexities that arise from the intersection of various privileges and disadvantages.
- e. Acknowledge that the perception of privilege and valued traits can evolve over time. Be aware of shifting norms and values and consider how these changes impact power dynamics.
- f. Recognize that everyone, regardless of their position, can unintentionally contribute to the oppression of others due to ignorance. Actively seek to identify and address blind spots in your understanding and interactions. Foster an environment that encourages open dialogue and active listening. Strive to understand the lived experiences of others and create space for diverse perspectives.

Being cognizant of power and privilege is an ongoing process that requires self-reflection, adaptability, and a commitment to creating equitable professional spaces. By acknowledging our own privileges and staying attuned to the dynamics at play, we contribute to a workplace culture that values diversity, inclusion, and mutual understanding.

3. CHALLENGING IDEOLOGICAL POWER THROUGH CRITICAL ANALYSIS.

They felt that I had lied to them about my capability of doing the job.

I was somehow the untruthful one.

They were right. I was wrong.

If you try to fit in you get further pushed down.

If you raise it, you're seen as a troublemaker.

In navigating the realm of ideological power, the ability to critically analyze information becomes paramount. Ideological power operates subtly, often without awareness, shaping narratives and controlling ideas. To foster a more honest and inclusive understanding, particularly when dealing with professional paperwork or colleagues' accounts, it is imperative to approach information with a heightened level of awareness:

1. Recognize Official and Personal Purposes:

- What is the stated purpose of the communication?
- What personal motivations might be influencing the narrative?

2. Evaluate Inclusiveness and Emphasis:

- Are all relevant details included for the official purpose?
- What details are emphasized or de-emphasized in the story?

3. Understand the Author's Perspective:

- What is the author's point of view?
- Is the narrative one-sided or presenting a balanced account?

4. Probe for Institutional Influence:

- What does the story support? (e.g., institution's function, credibility of individuals, legitimizing actions)
- Who is being criticized or punished in the account?

5. Consider Non-Verbal Cues and Context:

- What non-verbal cues or contextual information are not mentioned?
- What gaps or missing information exist in the story?

6. Assess Credibility and Truthfulness:

- Does the story appear credible and truthful?
- How are people or behaviours categorized in the narrative?

7. Question Categorization and Punishment:

- Is the object portrayed as problematic, and if so, how?
- Who is being punished in the story, and in what way?

8. Explore Authorship and Perspective:

- Who authored the story, and does their perspective always accurately represent the other person?
- Why did the so-called 'bad guy' make the choices they did?

9. Consider Trauma-Informed Perspectives:

- Could behaviours or traits be linked to trauma responses?
- Could the subject be acting out a position imposed on them?

10. Cultivate Critical Reading Skills:

- Practice reading documents, articles, or listening to speeches while consciously applying these questions.
- Allow this critical analysis to become an automatic skill, enabling you to identify gaps and nuances in narratives.

Like learning to see an alternative view in optical illusions, you can dismantle the mechanics of discrimination and develop a more nuanced and critical perspective by applying such questions to your thought process. This practice contributes to a heightened awareness of ideological power and promotes a more comprehensive understanding of the narratives we encounter.

4. PRACTICE ASSERTIVE COMMUNICATION AND ETHICAL BRAVERY

I was just daft, Teachers would make comments like that

I could be the class flea bag. That could be my role.

'Nobody could call them on anything'.

Recognizing and addressing oppressive discourses requires a commitment to assertive communication. Here are directives to guide you in navigating these conversations: Clearly express your concerns or objections without unnecessary softening. Choose words that convey respect without compromising the strength of your message. Embrace assertiveness over gentleness when challenging perspectives. Assertiveness communicates confidence and seriousness and can actually be received as less offensive than general messages which seek to challenge covertly. Take ownership of your objections and concerns. Clearly state, 'No. It's not fine. I'm not okay with that'. It's okay to acknowledge insecurities about challenging others' thinking. You can always state that raising objections makes you uncomfortable but you think it's important to speak up. Recognize that being true to your objections contributes to a more inclusive and understanding environment and gives permission to others to speak their minds.

It always surprises me how often I'll take a risk and speak out against something only to find that there were several other people sitting nearby thinking the exact same thing but didn't take the risk to voice their thoughts until they saw someone else do this. Be that person.

Remember learning to say what you think takes practice for many of us. Assertive communication is a skill that requires practice and refinement. By confidently owning your objections, you contribute to a culture where diverse perspectives are acknowledged and respected. Embrace the opportunity to be direct, clear, and respectful in your communication, fostering an environment where everyone's voice is heard and taken seriously.

5. VALIDATE

What they said was clearly more correct,

Everything. Every. Single. Thing

Making me feel that what I was saying was invalid.

Nobody would listen to my experience.

I need a feedback cycle.

Like, 'you do understand.'

Fostering the ability of individuals to identify their own wants and needs is paramount for overall well-being. To do this we must acknowledge the myth that the 'expert' knows what is best for all people. That means accepting our own limitations to decide what is important for another person. In my view it doesn't matter if we know the other person, what is important is that they know themselves and we can facilitate another's self-knowing by allowing them to teach us about themselves. But we must approach this from a genuine place of curiosity and willingness to listen and learn.

A major theme to emerge from this research was the participant's experience of disconnection from themselves as others applied narratives of their own choosing to them. Rather than dictate what is true of someone else, we can practice acts of validation. The concept of mirroring, rooted in child development theories, plays a crucial role in shaping self-awareness, emotional regulation, and healthy relationships. To facilitate the development of these essential life skills, you need to hold in mind the importance of simple validation. Recognize

that the ability to identify one's own wants and needs is a foundational life skill. Understand the impact of this skill on personal growth, emotional well-being, and relationship building.

Avoid Invalidating Needs: Understand that teaching self-identification is not achieved by convincing individuals that their needs are unreasonable. Encourage individuals to explore and understand their emotions and needs without judgment. Positive mirroring includes being aware of our own bias and privilege, so as to not make critical judgments on that which might simply be a cultural difference. An example I come across is that neurodivergent children are often perceived to be much more attached to their parents than what is considered normal. Validating is about acknowledging how someone feels without thinking that how they feel is wrong. You can offer a safe secondary environment by not challenging the primary one. Understand 'safe' to mean non-judgmental, non-demanding, and allowing the child to decide how they engage with the environment. Understand also that what society sees as normal development is not necessarily right or healthy development. Indeed, encouraging someone to adhere to what is 'normal' may in fact be unhealthy for them. People to progress at their own pace, support the individual journey.

Fostering self-identification and emotional well-being in people involves recognizing the power of mirroring. It can feel that we are not doing enough if we are not directing or challenging, but providing recognition of the individual can support healthy development and individual growth contributing to the development of well-rounded, self-aware individuals capable of navigating their own emotional landscapes.

6. CONNECTION FOCUSED APPROACHES

She gave me a perplexed look
a, 'What are you talking about?' look.
I have this deep fear that I'm wrong.
that's not even their experience,
If you're not going to listen to me,
I'm not going to listen to you.
I cannot make room for someone else's experience.
there's just the disconnect.

She showed no compassion no curiosity.

I could see how much attention the others were getting.

It's very objective driven.

People are not seen as people.

Instead of noticing how I was she just shouted,

I'm telling you my experience, you're not listening.

Recognizing both the prevalence and harm of normative bias, it's crucial to avoid trying to change a person's behaviour based on a desire for them to fit in with social norms. Instead prioritize connection, understanding, and individual well-being. To facilitate stronger connections encourage environments that differentiate between behaviour and personal identity, promoting self-worth independent of actions. Recognize that a focus on 'correct performance' as the sole source of human connection can lead to the development of shame and exacerbate trauma, causing individuals to suppress distress and perform for external approval. Prioritize deeper relational frameworks over superficial fixes.

Depending on the remit of the work you do, there may be more or less need as individuals to follow rules and tick boxes. But when imposing demands of the institution do so mindfully by genuinely allowing individuals to choose and consent to the relationship they have with the institution. As an example of what I mean: there was a time when my don didn't attend school because the expectations of the school were too much for them. For a while we could negotiate some adjustments but at some point the relationship broke down. My don started becoming what would be termed 'school resistant'. It was a surreal experience. I had a six year old who was physically refusing to go into school. For a short time I would carry them in. It felt surreal to carry someone, literally kicking and screaming, into a place they didn't want to be. It felt abusive. The accepted discourse was that it was not abuse because children are supposed to be in school. It was good for them and as a parent I was 'keeping them safe' by dragging them in. The term consent wasn't used in situations like that.

But the reality - which my husband and I felt - was that I was forcing them to be there. I was teaching them that the bigger person made the choices and their 'no' held no power. I regret ever doing that to them, but I did it, until one day I decided it wasn't right. Not taking them to

school was not going to harm them but dragging them in was. A six-year-old gets to have a choice. This is not something everyone agrees with, but as a parent my goal was to raise a person who would know they were entitled to say 'no' when they didn't want to be somewhere. I wanted to raise a person who went to school because they wanted to, because it was for them. We homeschooled for a while and when they were twelve they said they wanted to go back to school. I discussed the reality that school was a place where there would be expectations and some we could adjust and others not. They started again with the understanding that they could always choose to leave, and I would respect that. This is not to say I was not scared of what their life might look like if they never wanted to go to school. But they are individual persons, and I can't control everything forever. I needed to give them the freedom to make choices for themselves. The autonomy they had and still have is: do they want to go to school and conform to the requirements of wearing a uniform, sitting in class and following institutional rules? It felt radical to give them a choice, but I did - and they choose to go and tick the boxes and understand that they have autonomy in how involved they want to be in the school institution.

I advocate for a more comprehensive approach that considers long-term well-being and autonomy. Forcing people into compliance may address immediate concerns but fail to support a person's overall well-being. Instead, we can explore what the individual wants for themselves and work collaboratively to achieve it. It is important to recognize that there are bigger harms than not fitting into institutional norms, such as shame, trauma and loss of self. Consider the bigger question of what makes a life meaningful? It seems that so much of what is demanded of people is about basic survival within the institutional culture. Learning to sit still and follow rules. I don't believe we can build a meaningful life from that alone. Emphasize the unique needs and aspirations of individuals over standardized solutions. Recognize that personal growth and fulfilment extend beyond basic care needs and require tailored, individualized approaches. Resist dehumanizing tendencies by considering the impact of imposed regimes on yourself. By adopting these directives, professionals can contribute to a shift in approach, moving away from one-size-fits-all interventions and embracing holistic strategies that prioritize connection, individuality, and long-term well-being.

Why aren't I authentic?

Why can't I be Spontaneous, interconnecting with people.

I need a person to be open and communicative.

I feel it, but I don't know if the other person feels it.

I don't know if I'm actually connecting with them.

Helping other people

felt like a way I could rise above

my own fears and challenges.

Being helpful just

felt like a way to save myself.

A common viewpoint I've encountered in traditional therapeutic guidelines is that self-disclosure is unnecessary and unprofessional. While there's logic to this approach, it may not be the right way to work with people who have suffered from feeling 'othered'. These individuals need connection more than anyone. Being a 'blank slate' can deepen their wounds rather than healing them. From my perspective, having experienced years of mistrust in myself and others, I've found that a genuine expression of empathy and understanding goes a long way in building trust. Autistic individuals often have a need for clear and transparent verbal communication, which may be a result of years of unintentional gaslighting. Clients who have been badly othered often find explicit stories examples of how others relate to them healing. This can be seen in Bob's accounts of reading Finkle's book gave him a world beyond the 'smallness he felt.'

When the topics revolve around mental health and one person is expected to be the professional, it becomes tricky to determine how much of the therapist's self should be revealed. I encourage training institutions and organizations not to impose rigid rules about sharing or not sharing personal experiences. Instead, it should be up to the professional - and training should focus on how professionals can make their own choices regarding what and

how much to share. In essence, we professionals should be taught how to think for themselves rather than being told them what to think.

Another important point for professionals to consider is that when someone is in a state of extreme hyper-awareness, as traumatized individuals often are, being a blank slate is nearly impossible. They will pick up on more than you can hide. It's better to be transparent. This provides people with a clear context for what they are sensing. Openly sharing what you think and feel, and explaining any misinterpretations, helps the other person understand the situation better.

For example, if I, as a therapist, am feeling stressed - and the client assumes they did something wrong - it's better for me to explain the source of my stress rather than pretending to be a perfect professional and making them feel their insecurity is all in their head. It might even mean offering an apology for bringing stress into the room. I'm not perfect - and it's better to provide that information than let the client's anxiety go unaddressed. Many of the things we hide about ourselves are to avoid admitting our own insecurities, and when we hide our imperfections, we transfer that anxiety to the other person.

In my view, being human means not adhering to strict rules about what is right or wrong. Deciding how much to share should be a case-by-case consideration to manage risks to ourselves and others.

People come in varying degrees of self-referencing and other-referencing. Some people know what they are thinking and feeling but spend a lot of time questioning if their point of view is rational or legitimate. Others have moments of feeling safe enough to tell me how they are feeling or thinking, but then feel insecure after opening up. They might then become apologetic: 'I'm sorry for burdening you with X'; 'I hope I didn't offend you when I said Y'. My response is to first reassure them that they were okay to share what they did, but also to name that which they are feeling insecure about.

Common fears are around topics that include sex, anger, or politics. On one occasion someone shared the name of a manga with me, which many would find offensive. It was so shocking that just hearing it made me laugh out loud. It was exactly the sort of thing my friends would have been laughing at when we were in our twenties. I repeated the title back to them (which is

pretty bad.) They looked shocked to hear the words come out of my mouth. Then I said, ‘You know, I’m human too’.

It’s been through small, often seemingly ‘unprofessional’, transactions like this that I have witnessed the most amazing transformations of self-trust. The more I become a safe other, the more they start to trust that their interests and curiosities are okay. There is such a fear of being stigmatized for being inappropriate, dysregulated and crazy. I’m so tired of this. *These are my people.*

8.

MODEL HUMILITY TO BUILD TRUST

I need someone to be there

and present.

Not an expert,

not somebody perfect.

Just somebody to listen.

It is imperative to shift towards a more human-centric mode of working that values transparency of our own humanity and foster genuine connections with individuals who have experienced feelings of being Othered. Some ways of doing this include using self-disclosure as a tool for connection. You might consider sharing your own vulnerabilities, experiences of frustrations or shames with people you support. ‘I get frustrated too.’ Or ‘I feel anxious at times’. ‘I get it wrong’. Recognize the healing power of genuine expressions of empathy and understanding. Be careful not to apply your experience onto the other, or to belittle their experience by suggesting that what they are going through must be felt in the same way or to the same degree. I suggest *offering* my experience whilst at the same time acknowledging that I can’t know exactly how they feel. If I speak to a client who has experienced bullying I might say something like, ‘I know I won’t have had all the same experiences you have and it may have landed differently for me, but I wanted to share that I suffered a lot of bullying when I was young and it really stayed with me for long time. It’s not okay, but you’re not alone’. I might also start by asking for permission to share something about myself. I remember when I was in high school, I would talk to my Latin teacher like a friend. I would tell her about my home

life and my life stresses. Then one day she told me about an argument she had with her husband. I don't think she went too in depth, but her sharing that was such a comfort. Someone valued me enough to share something of themselves with me. Also, an adult who seemed to have it all together was telling me she was human. I needed to know that. It did so much good to have that exchange. Do consider that real life stories of our humanness can be deeply healing for someone who has experienced Othering.

Encourage training institutions and organizations not to impose rigid rules about sharing personal experiences. Promote the idea that professionals should make their own choices regarding what and how much to share and shift training focus towards teaching professionals how to think for themselves and make informed decisions about self-disclosure based on individual needs.

Another reason for some self-disclosure is that extreme hyper-awareness, common in traumatized individuals, which makes being a blank slate nearly impossible. Offering some transparency about ourselves allows the hyper-vigilant observer to make sense of us, provides a clear context for what they are likely already sensing and then reduces anxiety and misinterpretations. In these instances, small, seemingly 'unprofessional' transactions can lead to significant transformations in self-trust.

Also, allow for some 'past timing' just talking about that which is interesting, not necessarily that which is prescribed as learning or therapy. Let the person know their interests and curiosities are valid and accepted. Whilst that may seem trivial, the significance is in the connection that is happening. This human-centric approach promotes healing, self-trust, and a shift away from stigmatizing perceptions of 'inappropriateness' within professional spaces.

9.

SAFE SOMATIC MINDFULNESS

I was sat there, pen in my hand.

I felt so separate. like it wasn't real.

When we're in emotional overload

there's almost like a circuit breaker,

I see that as a mode of preservation.

rather than genuine unfeeling or uncaring.

Because we do feel things far more strongly.

sick, panicked, headache, dazed.

And sometimes it can just get too much

Recognizing the impact of repeated invalidation on individuals' connection with their emotions, it is essential to guide them towards rediscovering and understanding their feelings. Incorporating somatic awareness and mindfulness can be powerful tools in this process. In line with the principle of informed consent highlight the importance of understanding mindfulness as a *choice* to slow down their instinct to react so that it isn't inadvertently used as a form of dissociation in moments of threat to wellbeing. In other words, mindfulness is an act of noticing without acting but sometimes we need to act. People who have had their experiences invalidated may not give themselves permission to react when they need to. Encourage the incorporation of safe mindfulness by posing questions such as 'Is this hurting me?' or 'Do I need to take action now?' ensuring the decision aligns with the individual's well-being.

First understand that autism does not keep an individual from knowing themselves. We have the capacity to explore and understand our emotions. Help people connect with their emotions by first becoming aware of physical sensations. Use questions like 'What do you feel in your body right now?' to initiate exploration.

Foster mindfulness of touch, sight, sound, taste, smell, and internal bodily sensations and emphasize the role of sensory awareness in anchoring attention in the present moment. The aim is to introduce people to their ability to use their sensory input to deepen their connection to immediate experiences. As you do this encourage the person to explore *their* meaning behind identified feelings. Ask open-ended questions like, 'What does that mean to you?' to facilitate deeper self-reflection.

By implementing these directives, professionals can support individuals in reconnecting with their emotions, using somatic awareness and mindfulness as tools for self-discovery and self-regulation. It is essential to approach these practices with sensitivity, encouraging clients to explore their feelings while exercising caution and promoting mindful decision-making.

10. PSYCHOEDUCATION

I didn't have any boundaries when I was younger.

I wasn't told anything about what was okay and what wasn't.

Now, through all the psychotherapy training

I do have more awareness of myself.

Philosophy taught me to articulate myself.

I say it in their language

That's a skill

to be able to explain experiences.

Usually, people are quite understanding.

Sarah and Bob went into psychology fields. Jen went into social services. Ziggy was very philosophical. They all seem to use theory to make sense of their experience. Offering language and theoretical frameworks to the individual through which they may start to articulate their experiences can promote self-awareness and enable people to advocate for their needs and ensure they are better understood by others.

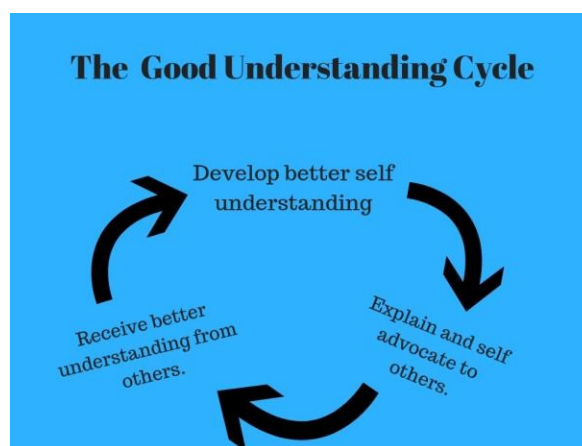


Figure 10 The Good Understanding Cycle

Psychoeducation can be delivered by mental health professionals, such as psychologists, psychiatrists, counsellors, or social workers, as well as through educational materials, workshops, support groups, or online resources. This can be offered to anyone at any level. By making theory available to the individual, they are empowered to tell their own story. I always offer any theory along with the message that they are free to agree or disagree or even alter the theory in ways that feel right. Theory is created by human beings and will be limited and imperfect in how it articulates the experiences of others. It improves over time because people take the ideas that are out there and challenge or expand upon them. Finding theory that feels like a good fit, or challenging theory that doesn't seem quite right, are ways that the individual will become better acquainted with how they are feeling.

Psychoeducation aims to equip individuals with practical skills and strategies to manage their mental health. This may include stress management techniques, problem-solving skills, communication skills, relaxation exercises, or strategies for self-care and well-being. Psychoeducation helps reduce stigma and normalize the experiences by offering a shared vocabulary. Additionally, the act of seeing self-understanding can set the foundations for someone to become analytical and approach self-understanding as something they will work on throughout their lives rather than as a one-off experience where they get all the answers. People are complex and changing and therefore this needs to be a skill the person owns, rather than something which is given to them by another.

11. RECLAIMING THE SELF STORY

Writing

I can take my time.

Formulate everything carefully.

Understand that mis-storied experiences can lead to internalization of false narratives, impacting self-perception. Storytelling can be an incredibly powerful tool for healing and rebuilding a coherent sense of self. Using previously mentioned techniques for de-Othering facilitates open conversations about individuals' self-narratives, addressing any fears they

may have. Acknowledge that the rejection or denial of one's self-narrative can evoke feelings of shame.

Encourage the person to consider the impact being mis-storied by others has had on them. You might use the Power Threat Meaning Framework questions as a tool for initiating the process of writing one's story. This encourages individuals to reflect on questions that explore power dynamics, threats, and the meaning of their experiences. Using the PTMF questions as a starting point encourage the person to write or tell their story in the way that feels most meaningful to them. This can be done in a variety of ways such as using metaphors, visual representations or music. Provide ongoing support for the exploration and articulation of personal narratives. The aim is to foster healing and rebuilding a sense of self. This can be incorporated with somatic mindfulness as the person tells their story to help them connect with their authentic experience.

12. EDIT THE STORY

Go
back
and
edit

One of the decisions I made when interviewing participants was to do four interviews and space them a week apart and with each new week I asked if there were any reflections about the previous week's questions. I wanted to provide the participants with an opportunity to edit or amend or add to anything they had said. For some this would be ethically questionable if they subscribe to the discourse that what is said in the first instance is the most true. But I find that when working with marginalized people who have not had a strong sense of self, it is necessary to give additional time for them to think about and re-articulate their experience. And when there is incongruence between one account and another it does not mean that there was dishonesty- it means that understanding how things were for them takes a bit of time because they did not have this previously in the early developmental years. As Bob said, he liked the writing process because he could go back and edit. My suggestion would be that when doing narrative work with a person, there is the initial story created (that in itself may take time); but then there is a benefit in allowing more time to elapse and coming back to this story to see if

there's anything the other person wants to change. This is a way of processing, solidifying our thoughts and feelings, and a step towards being able to understand where our life experiences fit within our sense of self.

I don't have a format for questions to be asked like the above, where one might use the PTMF questions (Boyle and Johnstone, 2018). I would simply ask, 'Does this still feel right to you?; Is there something you would like to change; Do you have a different understanding of the story now?; Is there something you would like to add?' In doing both this exercise and the original narrative story exercise I think that it's important to consider values and frame of reference. What are the underlying explanations for actions and experiences? The PTMF asks the question - What did you have to do to survive? And I find that this is a good question because it seeks to understand the behaviour or perhaps it just seeks to name it as a survival behaviour. Another question that might be helpful is: 'What has helped you to heal?'.

CHAPTER 13: TALKIN' 'BOUT THE 'TISM'

Me:

'How was school today?'

My don:

'Someone was vaping Blue Raspberry
in the gender-neutral toilet again.'

'Right.'

Things are always changing. What we consider normal today may not be very soon. Also, what is 'weird' or 'disabled' now, might not be very soon. With this in mind, how can we work today to provide the best possible support for people despite the ever-changing understanding of normal? Another way to understand this question is: What life skills do people need regardless of the cultural norms?

CONTRIBUTION TO THE FIELD

As I come to the end of this thesis, I have reconsidered the overriding discourse that autism is a form of 'developmental delay'. As I write this, I think back to the metaphor I shared at the beginning - where I wrote that over-pruning trees could cause them to be developmentally delayed. I guess I already held this idea, but I find it landing with me again in a new way. My research has shown why this is not only possible, but *probable*.

We are often delayed in our development of self-understanding, and this has had implications for most areas in my life. But I do not see this delay as being the product of autism. Instead, I see it as the result of growing up in an environment where an individual's way of perceiving the world is often rejected. I propose that many commonly thought features of autism, such as a lack of empathy, anxiety, difficulty with expressions and emotional dysregulation, may be better understood as trauma responses. I further propose that this misconception has shaped the clinical descriptions of autism, leading to oppressive treatments for autistic individuals and

their families. This not only disables autistic individuals, but also hinders the support they might receive from family members and friends who have been miseducated about autism.

In Chapter 3 I shared the DSM's (2013) definition of autism which read: 'Traits may not be seen until the environment exceeds the person's ability to cope'. I believe this statement tells us that it is not actually *autism 'traits'* which are diagnosed but rather expressions of the suffering experienced by autistic people. Because, if we accept that people have differently wired brains, and some brains are autistic brains, then an autistic person is autistic from birth. *Autism* does not develop in certain environments. *Suffering* develops in certain environments. The current medical discourse on autism is that it only needs to be named if it is evident to the observer. In other words, if the autistic person's suffering is not witnessed then there is no need to name it.

The consequence of having this be a diagnostic criterion is that autistic people have to 'break' before they have a chance of receiving the understanding which all people require. After the person suffers enough to have their autism identified, the support is then focussed on helping the person to cope rather than offering support to help the individual know themselves better. I hope for a day when we might start to recognize autism and other forms of neurodiversity as a way of being which can be legally protected without the need to be pathologized. After all this is exactly what happened with homosexuality.

Another contribution my research offers is the creation of TIFDA - the Trauma Informed Foucauldian Discourse Analysis (Uher, 2023) - a research method in which we can use Foucauldian principles to examine the power dynamics that influence accepted discourses alongside the impact these discourses have on the people who are subject to them. In my research it felt important to analyze the effect of discourses rather than to simply offer an academic overview of them. To me, the impact on a person's well-being was the whole point. To not look closely at how the person experiences discourses is to continue with the objectification in which we are stood back looking at the 'cogs' in the wheel, rather than acknowledging the problem with dehumanizing people

One of the strengths of this research is that it has captured personal accounts of the experiences held by autistic individuals, expressed in their own words and unpicked over time.

This is a strength that non-autistic researchers are often not able to provide when wholly relying on their own interpretation of meaning and experience. Although, the flip side of this is that a limitation to the research is it does not offer a deep exploration of what the professional was thinking or experiencing within these stories.

A potential next step to address this limitation might be to interview professionals around the messages and culture in which they work, conducting deep narrative research that offers space for critical reflection about what may feed into misunderstandings, judgments and acts that impact on neurodivergent people.

IMPLICATIONS FOR FUTURE RESEARCH AND TRAINING

With the above in mind, a good future research endeavour might be to seek a better understanding of what it means to have ‘unprocessed perception’ and how that might change developmental expectations or emotional needs at different stages in one’s life, as well as how that might change attachment styles and family relationships. Further research, perhaps in the fields of sociology or education, would be to look at how we might incorporate an understanding of these needs into mainstream systems which accept neurodiversity without Othering or segregation.

An implication for future training of professionals entering fields of service would be to privilege research conducted by autistic individuals and wherever possible have the training delivered by autistic people as a matter of ethics to reducing the act of objectification where those who are not a member of this oppressed group are speculating on and speaking about those who are members of the group. As I stated in chapter one, I do not have the type of autism everyone does, but there are some universal experiences all autistic people seem to share.

One way in which the professional can be encouraged to remain in touch with their own humanity, as opposed to detaching from their own innate ability to think and reflect in lieu of simply following instructions, is to develop their ability to think critically. This is a key skill for professionals to have when social norms of the times shift. Critical thinking can be taught by using the TIFDA method to critically evaluate written documents, reflecting on dominant discourses and normalized biases. Beyond encouraging a more robust and flexible ability to connect with those they will be serving, this also helps the professional to think both critically about the information they receive as well as to consider how they themselves are communicating with others. In my experience as a counselling and psychotherapy supervisor, I find that young therapists often have a sense that there are set rules and that myself or other experienced therapists hold the answers. I have opinions, but teaching someone that my rules and opinions are ‘right’ deprives them of fostering their own ability to evaluate and decide for themselves- a skill which is needed in day-to-day interactions with clients or service users. I also hold a strong belief that questioning current ethics and guidelines is in itself ethical. When a professional is unable to question the rules, this means the individual they serve and their

needs are not seen but must fit into the framework the professional has been taught to follow. That is scary and it is not ethical.

MY NEXT STEPS

My research has, in part, been about reframing how we look at autism. I have also shared parts of my story and my children's stories and have talked about the data breaches that happened to my son and myself and the court case that I've started.

In the last few months, as I have been writing up my research, I have created a seminar to share the findings of my research. I put everything from Chapter Twelve into an instruction booklet with worksheets. I called the seminar: 'Talkin Bout the TISM' (Trauma Informed Support Model). I hired a room at a local community centre, sold tickets and bought custom made tote bags that cost way too much to give to attendees. I decided the bags were a limited edition *not* to be repeated. Amongst my first attendees were psychiatrists, psychologists, teachers, parents, autistic people, people from the local authority. It was a small group, but I was flattered that so many professionals were coming to hear me talk about how they could improve their work with autistic people. This was hugely validating. Some days it's enough for me and others not. I understand what Bob meant about needing a world bigger than the smallness in his head.

LOOKING BACK

I have been litigating for the past four years. Basically, since the start of my PhD. The litigation process is long, and I had my earliest claims struck out. I started with an application for judicial review. That application was denied with the judge stating Judicial Review was a remedy of last resort and I should have filed a discrimination claim or a data breach claim. I then filed a discrimination claim. To me that was the more important point to make. What was done to us was an act of discrimination in which our status as a family with autism made inconvenient to the institution and led to certain professionals punishing us for expecting them to respect our rights. The judge struck out the discrimination claim saying I had waited too long to file such a claim. On August 2023 I filed a data breach claim. In the UK data breach claims can be brought for up to ten years after the breach occurs.

Litigation came in waves. I realized towards the end of my first year that my PhD was an emotional refuge from the trauma of litigation, and I used it as such as much as I could. When I didn't have to be in court I focused on my research. As Bob said, 'Instead of loser, achiever became my identity'. For me it was like the tide coming in and going out. Academic work meant achieving and litigation meant floundering because I had little control over the outcome. A win in court was a judgment that relied on the authorities to say what was right. Despite my ontological position within this thesis- that authorized discourses are not the end all and be all - I was asking the courts to tell the defence they were wrong. I was waiting for someone in power to validate my experience so that I didn't have to be ashamed of it. I was not ashamed of who I was, the only shame I felt was in having an incomplete story being told: One in which my son or I got mis-storied. Losses in court left the story incomplete. I started to realize after the early dismissals that I had to create a different way of winning that didn't rely on the agreement of those in power. I could not control whether others would listen, only whether I would speak. I wanted the light to shine so bright that the full story was on display. I decided my power was in telling the truth loudly and publicly.

To help with bringing the light, I could evidence every bit of my story. However, problematically, official documents and emails often have a footnote to the effect that the contents are only for the addressed recipient and should not be duplicated. But court documents are public record. This meant that anything I wrote into my court applications and 'particulars' (my account of what happened) would become classed as public record. So, I made sure that as I was writing these documents that I included *every* name and *every* detail I wanted to make public.

Everything I have written about what happened to myself and my son I am allowed to shout from the roof tops. With the help of the courts, whether they intended it or not, I have gotten a penalty free ability to tell the truth. I have gotten my win.

UNDERNEATH THE AUTISM

When I first started training to be a psychotherapist, like all students, I was given a therapist of my own to see as part of my training. I saw her for four years and returned to her occasionally post- qualification as needed. When I first met her, we made a plan for therapy which included creating a 'therapy contract' - a statement of what I wanted to get out of our work together. Our contract was to explore what about my way of being was due to my autism and what was

due to my life experiences. Effectively I was asking: Who would I be if I had a better life experience growing up? That was the question I asked in 2013. It felt at the time that I asked this question like I was attempting to untangle a mess of interwoven threads.



Figure 11 The Tangled Brain by Elsa Riva

I realize, after conducting *this* research, how fitting this image actually is. If autism is a predetermined difference in wiring and life experiences also shapes our neurology, then trying to distinguish which parts of ourselves are determined by genetics and which parts by relational experience is very much an act of trying to untangle a mess of threads. Without intention, much of this research has been about asking that same question.

A common discourse around autism is that there is a ‘real self’ waiting to emerge once the autism is dealt with. It’s a contentious discourse for many of us. But the idea that there was a more authentic self ‘underneath the autism’ wasn’t an idea I could immediately dispel because

there has been something in my life about getting to a more real me and relinquishing what is often classed as 'autistic traits'. Is there a self 'underneath the autism'? I think there is a self underneath the years of mis-attunement and misjudgments. I think the attempt to untangle these threads is an important step in recovering. But ultimately, what was needed, was to change the conditions in which I was existing.

Years of self-work to heal from trauma leaves me feeling my most authentic self. It doesn't mean I never feel upset or express my upset, but it means I tend to feel more self-referencing than other-referencing, and more confident in putting my own boundaries in place with others. That is how I have changed the environment in which I live.

I start to like the way my brain works. I see my long-term memory, heightened sensitivities and tendency towards unprocessed perception as my gifts; and I see my limitations with organizing information the way others would - which affect time keeping and compartmentalizing - as acceptable ways in which I am divergent from the typical. There is a wonderful liberation in learning to love and accept myself as I am.

A common discourse around autistic adults who seem to function in the world as it is, is that we have developed 'tools' to help us cope. This metaphor suggest that I have collected something to help me better navigate life. I have not. I have relinquished that which was hindering me in the first place.

I believe more and more people are identifying as neurodivergent because - as the DSM (2013) suggests - modern day demands are more and more *exceeding peoples' ability to cope*. With this in mind it seems like time to start talking about a TISM.

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