Has The Way Society Constructed Their View Of Autism Developed Or Changed Since The 19th Century?

By

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Abstract

This thesis explores and identifies the changes in the perception of the societal impact of social inequality between autistics and non-autistics, largely through the way non-autistics (the majority) treat autistics (a growing minority). This is addressed via a naturalistic integrative literature review covering the 19th century to the present day.

The aim of this thesis is to address whether the development of autism diagnosis has changed the social construct of autism or whether autistics have changed it for themselves. Further, the impact, if any, that has been made on any disparity between the two groups will be addressed. The researcher personal positioning is that of a medically diagnosed autistic, from a largely autistic family.

The aims are achieved by addressing sub-themes and objectives including; whether the medical diagnosis of autism has developed or changed from the 19th Century to the present day; whether the way society has constructed its view of autism has developed or changed from the 19th Century to the present day; the influence of medical diagnosis and the societal construction of autism upon each other and the developmental impact of this; the extent to which the changing self-view of autistics has led to a greater sense of community and self-advocacy.

The research is undertaken through an interpretivist lens supported by certain pragmatic practices. The methodological approach is primarily that of integrative literature review incorporating snowballing; archival research has largely been prevented due to Covid-19. The primary findings of this research indicate that there have been significant development in diagnosis, legislation, and societal construction pertaining to and impacting upon autistic individuals. The study concludes that while the gaps in perception of autistics and non-autistics are narrowing and disparities are

improving, there is some considerable way to go before an equitable social construction can exist, in which the role of autistic self-advocacy will be key.

Finally, the study determines that the interaction between all the investigated elements can be viewed as a closed loop with no one factor establishing dominance of influence.

Introduction

It is acknowledged that across the world there are different types of inequalities and prejudices, but for this thesis, only that between the autistic and non-autistic communities will be researched.

In the three main chapters (19th, 20th, and 21st Centuries) academic books, peer reviewed journals, and validated websites will be examined to identify and clarify how and if the medical diagnoses of autism, language as demonstrated through dictionary definitions, legislation and the social construction of autism has developed over these centuries. The researcher will look at all of these areas and ask the question of whether the development of the first three factors have changed the social construct of autism or have autistics changed it for themselves. This is explored throughout the literature sections, drawing the answers together during the course of the Discussion and Finding chapter.

This chapter will introduce the researcher's chosen subject areas, with an explanation as to why it has been selected, along with defining some of the key topic phrases, which will be in brackets.

Before undertaking this piece of work, the researcher undertook a background literature review to ascertain whether there were gaps in the literature pertaining to the social disparity between autistics and non-autistics. The researcher holds the opinion that as more has been discovered medically about the different strands of autism, autistics themselves have become aware of their differences from non-autistics, but many autistics do not see themselves as having disabilities. Some of the differences may be not enjoying large social interactions, taking things literally, finding certain fabrics uncomfortable to wear, and finding eye contact difficult. Of course, everyone has their own opinions, non-autistics may see the autistic as disabled, or different or in a lot of cases, if there are no prominent features of autism, may not even notice at all. Having found no significant evidence of this area of research being undertaken, the researcher has continued to research this topic to ascertain whether their opinion holds.

Autism is a spectrum covering many different ways of being. Each person remains an individual. These different ways of being may to some degree, include social interaction, empathy, communication, and flexible behaviour, though this is not a comprehensive list (NHS, 2019). Within the 21st Century chapter, under medical diagnosis, is a table of possible signs of autism taken from the National Health Service website (National Health Service, 2019). To what degree these affect the individual autistic person varies greatly from person to person (Help Guide, 1999-2020).

The term neurodiversity, “what a beautiful word, that encompasses the reality that God has many different ways to build a brain” (Seidel, 2008 cited in Solomon, 2008), it is claimed by Silberman, (2008) was coined by Judy Singer in the late nineteen nighties (Singer, 2017). Herself autistic, “a three-dimensional universe of behaviors as challenging to define as the notion of human personality itself” (Solomon, 2008) Singer created a new way of thinking about the condition previously thought of as a deficit, disorder, and impairment. She acknowledged that many atypical (not conforming to type) people had unusual skills and aptitudes.

The American Psychiatric Association's Diagnostic and Statistical Manual of Mental Health Disorders IV (DSM IV-TR) (First, et al., 2004) lays out the five medical terms covering autism: pervasive developmental disorder (PDD), childhood disintegrative disorder, Rett's disorder, Asperger's syndrome and pervasive developmental disorder-not otherwise specified (PDD-NOS). For many in the medical profession, the objective is to find a “cure” (relieve a person of the symptoms of a disease or condition) whereas a large proportion of the autistic community (group of like-minded people) see autism as a cultural marker (totality of the humanly created world) (Tylor, 1958 cited in AnthroBase, 2019) or an identity (Davidson & Henderson, 2010). This will be referred to and expanded later in this writing.

Throughout this piece of work, there will be an investigation into how the perception of social constructionism (Andrews, 2012) may or may not play a part in defining any inequality between these two groups or whether these two groups are simply socially constructed and do not in fact exist (Harris, 2006). This will be explored through the literature reviews.

Figure 1 below lays out the strategy for more than the entirety of the thesis, addressing as it does empirical studies. However, this diagram is still relevant and useful as it allowed the researcher to consider a variety of options before deciding that a literature review was the most appropriate. Step 1 is addressed in the Introduction: A broad understanding of the approaches. Step 2 & 3: Distinguish the area of investigation and approach, are situated in this chapter and the Methodology with rudiments of Steps 5 and 6: Discern data type and collection methods. Step 4: Literature review, constitutes the majority of the three main chapters, 19th Century, 20th Century and the 21st Century*.* The 21st Century chapter will also incorporate some participant led elements Steps 7-9: Where, when and from whom the data is coming, decide if ethics approval is needed, and data collection. As data has been collected from a variety of autism community based, open source, online forums, it is considered that ethical permission will not be needed as the information is already in the public domain (University of

Cambridge, 2020), as in the case of this thesis. Step 10: Findings, will be undertaken towards the end of each chapter, with a drawing together of this discussion and findings in the final chapter. Step 11: Write up findings. A literature review can be considered a truncated version of figure one, utilising only steps 1-5, 10 and 11.

In this chapter the researcher will start by laying out the wide-ranging theoretical frameworks and researcher positioning accessible and relevant to the researcher. This will be followed by a reflection upon the preferences reached and the motivations for those selections, leading to the chosen theoretical framework within which this research sits.

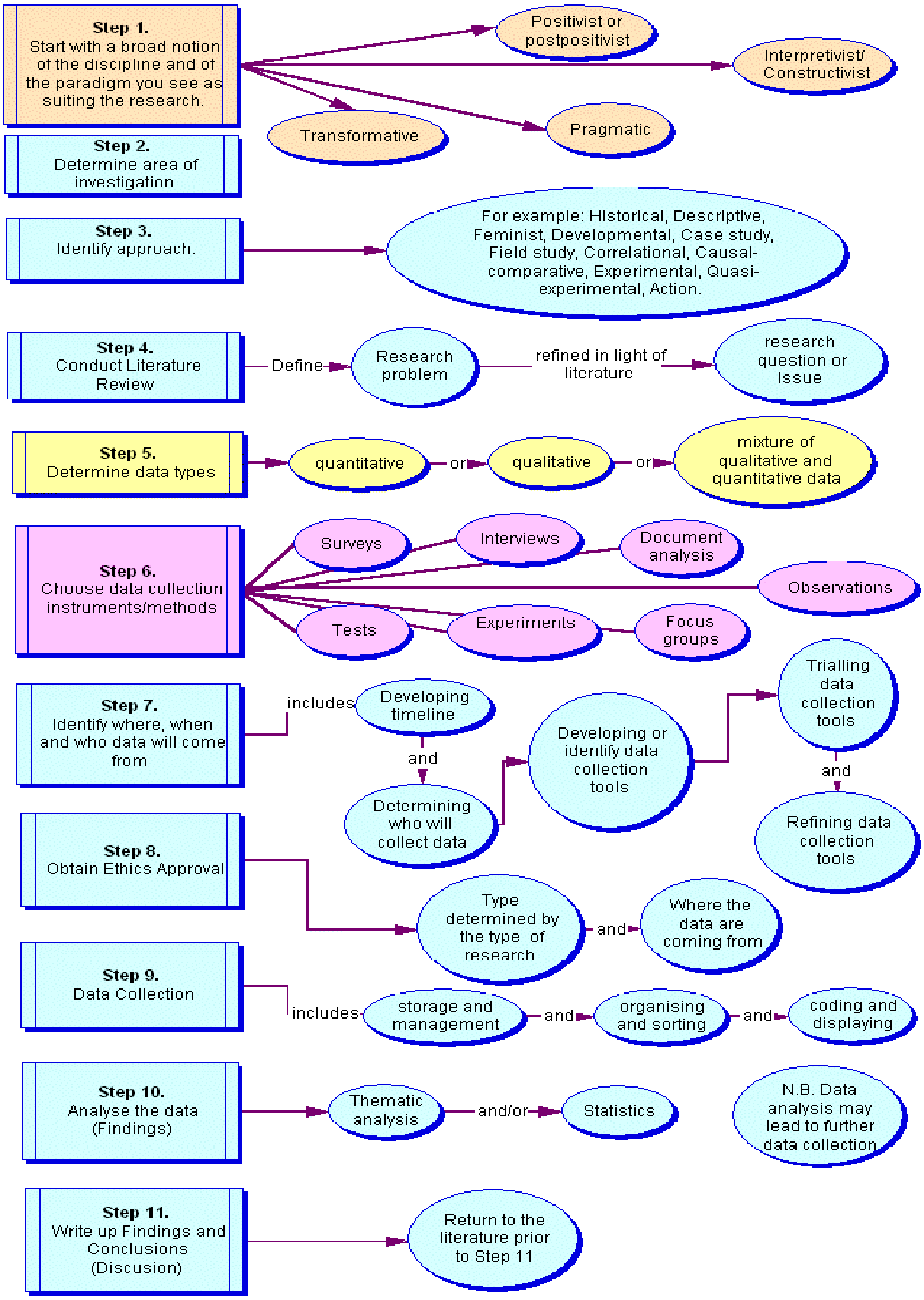


Figure 1: A Research Journey (Mackenzie & Knipe, 2006)

The aim of this thesis is to explore the development of autism diagnosis and whether it has changed the social construct of autism or whether autistics have changed it for themselves. A more in-depth discussion of the formation and parameters of this aim can be found later in this chapter.

Before we go any further let us look at what autism may be. The National Autistic Society defines the condition thus: “Autism is a lifelong developmental disability which affects how people communicate and interact with the world” (National Autistic Society, 2020). However, Mencap describe autism as “Autism is **not** a learning disability, but around half of autistic people may also have a learning disability” (Mencap, 2020, emboldening – Mencap’s). Autism is in fact a spectrum of many characteristics, including verbal and non-verbal abilities, understanding feelings and emotions of self and others, sensory issues, non-coping mechanisms in social or loud environments, disseminating information or instructions, repetitive thoughts, and actions (NHS, 2019a). Now let us look at what climate change activist Greta Thunberg and naturalist Chris Packham, both autistic, say about themselves. Thunberg states that being autistic is a gift and the reason why she is the successful climate change activist that she is. She attributes this to her logical problem-solving abilities and lack of interested in socialising (Wright, et al., 2020). Originally Packham kept his diagnosis, at the age of 40, of autism to himself; he struggles in social situations, preferring to live alone with his dog, though he also has a long-term but distanced partner, and yet he is a popular and well-known TV presenter. Chris describes himself as ‘a little bit weird’ and his girlfriend describes him as ‘like an alien’. His heightened senses can be overwhelming, as his commentary continually bounces from subject to subject. Though the researcher recommends watching Packham’s video (YouTube, 2020) they in no way endorse, agree, or disagree with the content. The researcher is using this an example of how in the past a celebrity might have masked being autistic, whereas now increasingly, a lot more celebrities and the general public are comfortable to let a wider range of people know.

1.1 Researcher Positioning

With a family (a group of two or more) background where sixty-six percent are on the autistic spectrum (variations of functioning and learning to the non-autistics), and the researcher's own medically diagnosed (medically examined and fitting medical criteria) condition (the way humans work) of autism, the area of autism was the natural and compelling subject to investigate. This then raises the question of whether autism is inherited or a birth defect. The researcher themselves relates as both 'normal' and 'alien' in this world we call Earth. Fundamentally, the result of this lifelong context in terms of this research is that the writing style may be different to that encountered elsewhere; autistic people have a slightly different sense of logic and prioritisation to non-autistic people, a more blunt approach which cuts to the chase. While the researcher makes every effort to meet and exceed academic expectations and rigour, it is inevitable that the result may be moderately more accessible for an autistic person, or somebody with great familiarity with the various autistic styles than those who are less familiar. This has no bearing on the validity and quality of the work, which stands or falls on its own merits.

Theoretical Framework

Doctoral students live in fear of hearing these now famous words from their thesis advisor: ‘‘This sounds like a promising study, but what is your theoretical framework?’’ (Lederman & Lederman, 2015, p. 593). Though the student may go in pursuit of a theory to validate the proposed research, the exploration is frequently unproductive since the researcher has a misconception of what a ‘‘theoretical framework.’’ is. The framework possibly will be a theory, but not necessarily (Lederman & Lederman, 2015). Qualitative research hypotheses are contained in an idealist standpoint (Bogdan & Biklen, 1982, cited in Lederman & Lederman, 2015). The researcher will be considering four aspects of a theoretical framework: Ontology: a way to explain our being; Epistemology: a way to explain human knowledge, Phenomenology: a way to explain human experience and Axiology: values and ethics.

Grant and Osanloo (2014) suggest that a theoretical framework differs from a conceptual framework in that it is taken from a previously accepted theory or theories from within literature. It is then left to the researcher to decide on how they utilise this theory to their research. A conceptual framework, on the other hand, is much more about how the problem will be examined and the direction the research will take (Grant & Osanloo, 2014).

We all have our own assumptions and ideas on how to formulate our research. These beliefs will have been constructed through our schooling, reading, social interactions and conversations with other academics. As we become conscious of these assumptions, we must take time to analyse them and decide which theories are appropriate for our research

2.1 Ontological/Ontology

Ontology refers to a thorough explanation of being (Cruickshank, 2003). Ontology is involved with the landscape of our existence, alongside the construct of reality. The researcher questions the nature of reality. Their reality may not be someone else's reality. For example, the interpretation of a conversation, or the conception of a plan or outing. From an autistic's point of view, their view of the world is often seen through a mask of trying to fit in to a non-autistic's world. Therefore, the researcher's state of being (ontological positioning) leads not only to the starting point of the research but its relationship to epistemological and axiological framing. Were we to initiate it into our framework, it would be positioned in conjunction with epistemology, informing the theoretical viewpoint, for respective theoretical perspectives exemplify a specific way of understanding "what is" as well as a certain way of discernment (Crotty, 1998). Ontology classifies what categories of entities establish reality. It interrogates the authentic characteristics of entities, exactly how and why are they created (Resca, 2009). The researcher's world view therefore governs the selection of the research proposal (Saunders, et al., 2009). It can be argued that ontology is often neglected, in favour of the moderately easier concept of epistemology (Resca, 2009), however, ontology gives a sense of the "content" of our being and the "relation" between the elements to our understanding (Resca, 2009), which lends to the researcher a certainty about the nature of their findings.

2.2 Epistemological/Epistemology

Pertaining to epistemology, from the Greek word Epistẻm, meaning knowledge, a branch of philosophy that investigates the origin, nature, methods, and limits of human knowledge (Creswell, 2014). Crotty (1998) describes knowledge as "how do we know what we know" (Crotty, 1998, p. 8). Thus, the researcher must distinguish, account for, and validate the epistemological position they have implemented (Crotty, 1998). Maynard (2013) discusses needing a philosophical approach in deciding the kind of knowledge that is used. These must be both sufficient and authentic (Maynard, 2013).

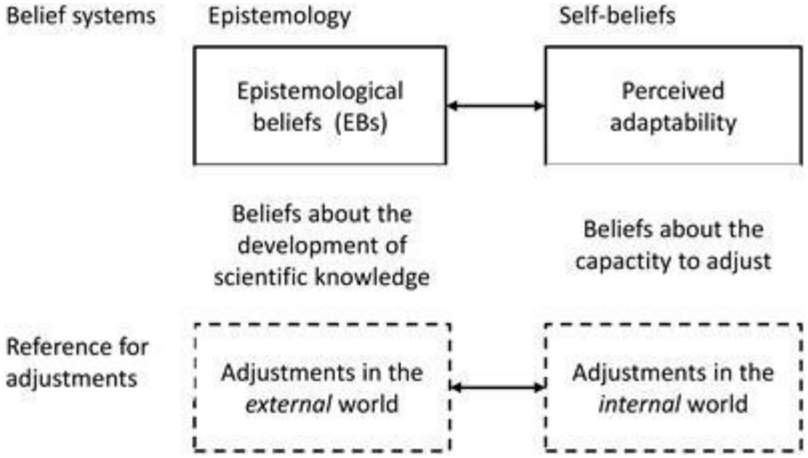


Figure 2: Conceptual model underlying the relationship between perceived adaptability and EBDE (Scherer & Guttersrud, 2018)

The model (figure 2) displays how humans perpetually reconstruct meaning and truth as all phenomena interact on each other. As humans learn more elements of their beliefs, it changes how they view these beliefs, hence it enhances their knowledge, making them less naive. This then changes how humans interact with the world, which then changes the knowledge others pick up and so forth.

Truth and knowledge are socially defined by the human experience within their own social construction (Counts, 1934). Increasingly, however, a different sort of explanation is sought, which is focussed through experience gained, rather than knowledge.

2.3 Phenomenology

Phenomenology is the study of phenomena. The way things manifest themselves, how incidents are inclined to materialise in our unique experiences, and exactly how we experience things, resulting in the meanings things have in our lives (Laverty, 2003). Phenomenology derives understanding, it can be argued, from experience, prioritising the question of what it is like to experience an event or phenomenon, in a similar way to epistemology constructing understanding from a more intellectual concentration on knowledge.

Within the context of this study, then, it can be said that figure 2, above in relation to epistemology is eminently adaptable to phenomenology and beliefs pertaining to societal phenomena and experiences. Thus, when one references outside experiences, rather than the gaining of intellectual knowledge, a phenomenological development in one's belief system can be said to have taken place. This then impacts on the interactions the individual has with other people, becoming part of their phenomena, and potentially causing them to adjust their internal world. This is one of the reasons why the limitation of this study to desk-based research, due to scale and Covid-19 is on the one hand, axiologically safer, but potentially frustrating despite the researcher having made peace with the fact that this is not action based research.

However, there is a fourth element, which is crucial to the integrity of a researcher, at both a personal and an academic level, which must be explored in order to ensure that an ethical balance is maintained.

2.4 Axiology

To ensure that the results of any research are credible, the values and ethics of both the participants (where there are participants) and the researcher themselves must be taken into consideration. The very reason that the given topic is being researched is that, to the researcher, this topic is in first place of importance, as is the way this research is undertaken. In the context of this very thesis the researcher has a large number of family on the autistic spectrum, including themselves, hence their concentration in the research they have chosen to undertake (Saunders, et al., 2009). Having stated this brings forth an awareness of a risk of bias, therefore, the researcher's integrity means that this researcher must hold themselves accountable in terms of a rigorous, honest approach to the research, and the risk of bias towards the subject matter.

To this point the researcher has explored the concepts of epistemology, ontology and axiology in their broadest senses. Below is an exploration of a variety of epistemological stances culminating in the researcher's chosen stance and the reasons for that choice. It has been established that ontology concerns the philosophy of being, epistemology is the philosophy or science of knowledge, and phenomenology is the philosophy or science of experience, while axiology is the philosophy underpinning the principles of ethics the researcher must consider.

Having addressed these issues, the aim of the next section is to explore a variety of epistemological stances in order to demonstrate the researcher's final choice of approach.

2.5 Positivism

Positivists, that is, adherents to positivism, hold the belief that there is an observable definitive truth (Creswell, 2014). Positivism is in agreement with the empiricist view that knowledge stems from human understanding. "It has an atomistic, ontological view of the world as comprising discrete, observable elements and events that interact in an observable, determined and regular manner" (Dudovskiy, 2018, s4.2.2.2). From a positivist's viewpoint the objective of their research is to generate impartial, unbiased epistemology, without personal attachment or vested interest (Willig, 2008).

Jueterbock (2009) argues that there is no influence between the researcher and the object of their research in positivism, thus, for example, although Newton observed the action of gravity, his understanding of this did not impact on the action of gravity. Thus, it can be argued that positivism is only tangentially relevant to any kind of social research, whereby the aim surely has to be some level of change in understanding or being. Positivism, arguably, does not work in the search for answers that involve ‘to some extent’ or where factors interact cyclically with each other (Bello, et al., 2014). It is suggested that while you could use positivism in this kind of research, the results would create a “naïve realism” (Bello, et al., 2014, p. 81). They also suggest that positivists think the world “conforms to permanent and unchanging rules” (Bello, et al., 2014, p. 81), which is the main stumbling block, as this limits its usefulness within a social sciences setting, which tends to view the world in a more complex way, based on experience, interpretation and context (Bello, et al., 2014).

2.6 Postpositivism

A reaction to the positivist movement; postpositivists hold the belief there is no definitive truth, especially when applied to humans, though there was a general detached truth but that it may be very problematic or even unachievable to patently ascertain it within the social sciences (Creswell, 2014). Groff (2004) finds the postpositivists’ perspective challenging, this is not because humans have to fathom how the world works for themselves, but it leaves them not discerning how to talk earnestly about dishonesty and inaccuracy (Groff, 2004). Postpositivism still concentrates on quantifiable data and interprets the findings contextually (Kroeze, 2012). On the whole, the character of humans favours absolutes, therefore the position of postpositivism may cause a feeling of insecurity in the researcher. Indeed, the same can be said for all stances with the exception of positivism. However, if a researcher can reconcile the instinct for absolutes with the uneasiness caused by the knowledge that there are no absolute answers, there are possibilities for an impact within social research. Examples of postpositivism in action or having a direct impact can be found in Parry, et al., (2001), wherein the researchers involved members of their target community in their postpositivist research design, leading to higher societal impact and long lasting results. The context here is health, which perhaps suggests an area where this approach might be most effective. In doing so, research participants may experience stronger feeling of ownership and agency, thus leading to more meaningful results.

2.7 Pragmatism

Used in mixed method research and the way research is undertaken, pragmatism is very open ended (Creswell, 2014). Creswell proposes that pragmatism is not so much a theoretical framework, "a thorough review of the literature" (Lederman & Lederman, 2015) as a world view, "a personal and historical point of view" (Vidal, 2008). Tashakkori and Teddlie (2010) express their opinion that it is not a theoretical framework at all, but a hypothesis of comprehension, or the way researchers approach their view of the world. Patton, cited in Tashakkori and Teddlie (2010), describes being pragmatic as emphasising practical issues of methodological appropriateness (Tashakkori & Teddlie, 2010).

This then means it is not so much a theoretical framework as an approach. Creswell declares, "you have a freedom of choice" (Creswell, 2014, p. 11), and that freedom is fashioned or restricted by selecting the methods, techniques and procedures that best converge with the requirements and rationales of the research. It is therefore not about discovering a truth, but about locating what mechanisms are appropriate at the time.

Both Creswell (2014) and Tashakkori and Teddlie (2010) voice that it is not regarding what is right and wrong, it is purely about what works. Pragmatism is real-life research, it acknowledges that there are no comprehensive philosophical solutions, rather it looks for practical solutions to make the project effective (Duram, 2012). There are two techniques in which a researcher can apply pragmatism to their research, they can operate it as a target, to discover what works, or the researcher can moreover use it as a way of deciding their research methodology.

When operating a mixed methods research approach, the researcher will use numerous varieties of data that deliver diverse types of knowledge. This in turn provides robust comprehension and conclusion of the presented research question (Creswell, 2014). Mixed methods research incorporates both quantitative and qualitative data into the area of research being undertaken (Shorten & Smith, 2017), to give more depth of meaning to the way the research in synthesised in order to create meaningful and useful findings and conclusions.

2.8 Interpretivism and Constructivism

The term interpretivism represents theories that examine how we acquire understanding of the world, which generally have confidence in translating or comprehending the connotations that individuals assign to their actions (O'Reilly, 2012).

Interpretivism is a paradigm which has far more relevance to social science and humanities than pure science (Creswell, 2013). If we look at by what method any illness is socially constructed, we will discover there are many social factors at play, these include culture, gender, religion, political economy, class, institutional and professional structures, and many more. These increase our society’s knowledge base whereby we construct our assumptions, treatment, and social meanings (Brown, 1995). Thus, another society may construct health and illness completely differently, based on the cultural, religious, and other customs and constructions deemed prevalent and acceptable. Logically, there is not one type of societal reality, but many. Rolfe, (2006), cited in Scotland (2012), points out that if reality differs from person to person, then the participants cannot always reach the same conclusion as the researcher (Scotland, 2012).

The differences between interpretivism and constructivism are acknowledged to be paper thin in terms of operation, leading to challenges in understanding how they vary from each other (Gorski, 2013). in a wider discussion of many of the schools of research laid out here, Gorski perhaps gives the clearest insight into the relationship between the two: he suggests that the major difference is not in their execution, but in their ontological stances, giving weight to the earlier assertion that ontology is the crucial starting point of all research. Gorski states: “Interpretivists draw a sharp line between the two domains [natural and social entities]; they argue that social reality is linguistically constructed (Geertz 1973; Winch 1958). The constructivists go further still. They see the natural sciences as linguistically constituted as well (Feyerabend 1975; Rorty 1979). For them, the natural sciences are just another realm of social life" (Gorski, 2013, p. 660). Gorski also suggests that interpretivism came first, in direct opposition to positivism; referring to constructivism, the standpoint that all things are created through language, is characterised as “the young upstart” (Gorski, 2013, p. 660). Interpretivism then, stops short of this, suggesting that only society is created through language.

2.9 Transformativism

Transformative research can be considered academic in intent, which is integrated with politics and policies concerning social change (Creswell, 2014). Further, “Transformative learning attempts to explain how our expectations, framed within culture assumptions and presuppositions, directly influence the meaning we derive from our experiences” (Mezirow, 1991, p. 8 cited in Taylor, 1998).

Every conflict, whether that is actual violence, or more peaceful or intellectual disagreement has an ever-changing set of contradictions and incompatibilities. Once resolved via the leaders, this does not necessitate that it is resolved *ad infinitum*, thus it is a never-ending circle (Galtung, 1996). Therefore, transformative research allows academics to engage with and fully enrol those subjects to various forms of perceived injustice to participate in solutions, or at least to transform their understanding, along with that of the researcher.

2.10 Social Constructionism

Social constructionism is based around how knowledge and truth is created. The social meanings are taken for granted within societies reality, based on agreed, shared knowledge (Andrews, 2012). Further, Berger and Luckmann (1967) argue that societies construct their own realities, based upon what has been repeated often enough to become the norm. Society is therefore constructed of habits (Berger & Luckman, 1967).

Andrews (2012) explores how knowledge is constructed rather than created. He looks at how different societies create meanings that may not be challenged for significant periods of time, such as the predominant western societal constructs of Britain and America as paternalistic capitalist or neoliberal societies, a view that has begun to be challenged, but has stood for many hundreds of years. Humans will read these conditions differently from each other. The way people communicate knowledge constructs differing understandings, as in the saying “glass half empty or glass half full”; in each scenario the glass contains the same amount but has opposing meanings (Willig, 2008).

Taking a slightly different approach to social construction, Foucault contends that all knowledge is established and socially constructed under the environment of power (Anttonen, 1999). This hints at what has become known as the Foucauldian idea of Power/Knowledge, where the two concepts are essentially linked and cannot be untangled, a sort of symbiosis (CoomberSewell, 2020a). Foucault taught that in actuality power necessitates relations, a more or less coordinated, hierarchical, synchronised collection of relations (Foucault, 1980). However, Foucault gives a much less focussed definition of knowledge than he does about the manifestations of power (Foucault, 1979) in mainstream political theories (Gutting, 1994). This means that it can be difficult to give explicit evidence for the knowledge elements of power/knowledge, as the knowledge (Canguilham, 1994) element is assumed rather than provable.

There are other approaches to research than these various sub-divisions of epistemology; the limitations of this research make discussing all of them unwieldy. however, it is worth spending a short amount of time considering one other branch, phenomenology, due to the fine levels of separation in terms of focus compared to epistemology. It is also worth acknowledging that within the school of phenomenology sit such approaches and ethnography and auto-ethnography, but this division could be viewed as slim, as these share much in common with their epistemological cousins, constructivism and interpretivism (Wall, 2006), as they all concentrate on the creation or discovery of meaning.

2.11 Researcher Position

Having defined and reflected on the major types of paradigms and theoretical frameworks, the researcher relates strongly to being a transformative thinker at their core. The researcher has always associated themselves with being an activist throughout their lives, now as an academic the researcher perceives that a transformative paradigm fits effortlessly within their character. Personal axiology sits within the ethical foundation of the researcher and other researchers, aligning their transformational research and their fundamental ethics. The researcher has an inbuilt and ingrained axiology in that all ought to be kind and consider each other with equity. This makes the researcher a transformational researcher for the reason that the world is not kind and does not behave towards people with equity. Since the beginning of time there has continuously remained a duality of 'Self' and 'Other'. This was not reliant on the classification of the sexes or upon any empirical facts (De Beauvoir, 1997).

The researcher has elements of philosophical and practical pragmatism; however, within this context, although they are a transformative researcher, their learning is changing them, correspondingly it has the potential to revolutionise the world's comprehension of autism. Additionally, pragmatism can be found in how they are selecting the documents that work for their purpose, addressing the circumstances within the set timeframe, for the researcher's argument. A good example of this would be through the current epidemic, Covid-19; pragmatists find as much as they can from archives, taking a pragmatic decision not to take an interruption until the archives re-open but to work with what they have. The researcher has also preferred an integrative desk-based study for the reason that it works in terms of the historical standpoint, therefore having a broadly interpretivist approach during these early chapters. Later, in the 21st Century chapter there will be more tentatively transformative elements as the researcher will be using forums to garner more information. Overall, the researcher will be using a moderately hybridised methodology; while sitting primarily in a social constructivist brand of interpretivism, elements of pragmatism, largely relating to containing the scale of the project have had to be introduced. These pragmatic elements are at a practical level, partly induced by Covid-19 whereby the researcher has had to make pragmatic choices concerning a curtailment of archive access in person. The researcher has had to concentrate on on-line and other publicly available resources. To summarise then, while the researcher is a transformativist at heart, there is an acknowledgement that under the scope of this research paradigm and the current Covid-19 circumstances, this cannot be achieved.

Rather, desk-based study approach has been created for pragmatic reasons in terms of ensuring that the research is likely to be effective in its goals, that is, the approach is the one that is most likely to be ‘what works’ (Tashakkori & Teddlie, 2010). To clarify, the researcher is not entering the philosophical world of pragmatism, whereby beliefs and interventions are evaluated on how well they are able to be practically applied. This version of pragmatism is the one much more familiar to the layperson, whereby the researcher can be viewed as taking a practical approach to achieving their goals, with little reference to a deliberate act of transforming attitudes or beliefs.

This researcher’s ontological position is broadly relativist as she does not believe in an absolute truth, only a construction of personal truths based on facts, knowledge, and experience, while epistemologically, she embraces interpretivism and pragmatism, limited by the scope of the project.

2.12 Research question definition process

The researcher has, through reflection and reading, explored the theoretical framework by questioning what is the: Problem, Purpose, Significance, and the Research Question? (Grant & Osanloo, 2014).

2.12.1 The problem

The societal disparity of understanding between autistics and non-autistics (Sasson, et al., 2017). Do the different cohorts, autistics, and non-autistics, have any knowledge of the other's worlds? How do they function in terms of cognitive strengths and weaknesses, interpretation of the meaning of the spoken word, non-verbal communication, routines, and expectations of the human beings around them?

2.12.2 The purpose

The primary purpose of this research is to ascertain from where the divergence between these two groups stems. This leads to a number of reflective thoughts which can be formed into the basis of research queries: Is it the medical diagnosis or the way society construct their understanding that leads to divergence? If medical diagnosis is responsible for the separation between non-autistics and those in the autistic community, then the strategy for addressing this gap must be focussed on the medical and associated professions. In order to examine this assertion/hypothesis, initially the discussion will utilise resources from the world of diagnosis and legislation. Starting from the 19th Century there has been consistent interference by doctors in the judicial system, and judge’s interference in the medical system (Foucault, 2003). If Foucault’s assertion is true, this would lend credence to the view that the medical-juridical influence is the predominant cause of divergence and othering. Thus, in starting the discussion here, the logical journey (through each century) is to begin with the diagnostic and legislative themes before moving on to the social construction of autism. Admittedly, there are other approaches than that of Foucault. One could address any philosophy of society from Plato to Kant and find a logical entry point to this question.

If, however, it is a societally constructed othering, then an approach addressed to the public not only of intellectual awareness, but behavioural and emotional connection becomes much more relevant to the way forward. There are many aspects to how society constructs meanings, including age, particularly in relation to how mental health and conditions such as autism are viewed. Age may also play a part in western society’s social conception of mental illness. Within the older generation there may be a belief that mental illness can be avoided by keeping busy and focusing on others rather than self. However, the younger generation may view mental health as part of everyday living and something that needs to be dealt with either by medication or therapy (Pilgrim, 1999). In a Royal College of Psychiatrists’ (2018) report they state that a generic approach to mental health has resulted in age discrimination (The Royal College of Psychiatrists, 2018) This can also be seen within different social classes (Pilgrim, 1999). The World Health Organisation outlines six key facts concerning young people and mental health. This includes the calculation that 16% of people aged ten to nineteen years old have mental health conditions starting from the age of fourteen (World Health Organisation, 2020).

This is relevant to any study of autism because of the condition's legal status as a mental illness to this day, despite being more accurately a state of neurology. This perhaps hints at much of what the rest of this thesis will explore; it raises the question of whether the socio-cultural and legal treatment of autism lags behind that of the medical profession, contributing to the perceived gulf between the acceptance of autistics by the neurotypical.

2.12.3 The significance

One only has to spend a short amount of time observing the interactions between autistics and non-autistics to conclude that there is a misinterpretation between these two groups in terms of the significance of verbal and non-verbal clues, their expectations of behaviour, interactions, and values. For instance, within the counselling room if the counsellor has no real knowledge or understanding of autism, the counsellor may therefore try and help the autistic person within a non-autistic framework. This would result in the autistic client trying to fit into a world they have little understanding of. This would cause both the client and counsellor distress and frustration (Hodge, 2013). This does not just apply to medical counselling scenarios but to all counselling, coaching and mentoring scenarios, whether medical, business, or social, as indicated by the researcher's undergraduate work (CoomberSewell, 2018).

2.12.4 The research questions

The researcher spent a considerable amount of time deliberating on these following questions. They took into consideration the knowledge of their own family's journey starting in the early 20th Century to the present day.

> Has the development of autism diagnosis changed the social construct of autism or have autistics changed it for themselves? What impact, if any, has that made on any disparity between the two groups?

This can be expressed as a number of sub-questions or objectives:

> Has the medical diagnosis of autism developed/changed from the 19th Century to the present day?
>
> Has the way society constructed their view of autism developed/changed from the 19th Century to the present day?

In the creation of these sub-questions the researcher has addressed the many nuances of the overarching research area. The question of whether society influences diagnoses, legislation, and other formal structures or rather, these areas influence society is a question that can only be partially answered. These sub-questions however, go some way to addressing the disparities and reasons for them, that autistics may experience in their daily lives.

In this chapter, the researcher has considered the definition and purpose of a theoretical framework, with particular attention to ontology, epistemology, and axiology. It has been established that the framework to be used here will be largely social constructionism with hints of transformativism and pragmatism. This will inform the next chapter, the Methodology - a set or system of methods, principles, and rules for regulating a given discipline, as in the arts or sciences (Creswell, 2014).

Methodology

This chapter concentrates on the development of the methodology applied in this research. This method has been developed within the context of the theoretical explorations and conclusions reached in the previous chapter.

This research will be conducted by using an online, desk-based study along with archive research, creating an integrative review critically analysing and examining the literature. An integrative literature review has many benefits, these include assessing the strong points of the evidence, identifying disparities in the research, detecting the need for upcoming research, identifying fundamental issues, producing a research question, identifying a theoretical or conceptual framework, and exploring which research methods have been used effectively (Russell, 2005).

Hart (2001) explains a literature review as selecting obtainable texts, published and unpublished, on the subject, which contain the appropriate evidence, conceptions, statistics and substantiates the particular perspective to satisfy the objectives or articulates the understandings on the features of the subject matter and how investigation is to be undertaken, and the successful appraisal of these documents in relation to the study being propositioned (Hart, 2001).

An alternative approach may have been a Systematic Review. The researcher discovered this would involve identifying published and unpublished evidence, selecting studies and reports, assessing the quality of each study, synthesising the findings in an unbiased way, interpreting the findings in a balanced and impartial way (Hemingway, 2009). On investigating this type of review the researcher took the decision that this would not be an appropriate system for this significantly dyslexic person within the context of these time scales, due to incompatibility with the researcher's neurological wiring. The integrative review is therefore the most appropriate methodology pragmatically, that is it works for both the researcher and the research, and axiomatically, in that it has integrity. Further, an integrative approach is highly suited to this type of research whereby the aim is to present a broad overview encompassing a wide range of sub-topics based around the themes encapsulated within the research and sub-questions. However, certain elements of a systematic review approach have been incorporated, as can be seen in the use of a PRISMA based process map in the appendices. This is *not* a systematic review, it is an integrative review, so to follow the PRISMA process slavishly would not be appropriate. There are areas, however, where the process provides clarity and useful 'scaffolding'

3.1 Why an integrative review?

The researcher has identified the gap in the knowledge during their pre-project research as mentioned in the introduction; the question of whether there has historically been a societal gap between autistics and non-autistics is not addressed explicitly in the extant literature. Further, there appears to be no existing scholarly body of work to identify if the gap, if indeed there is one, between autistics and non-autistics came about due to the changing medical diagnoses, or the social construction of autism. It was a growing awareness by the researcher of these issues and that these issues have not been addressed within the academy that led to the explicit questions as laid out within the Theoretical Framework chapter (chapter 2). It would be impossible for the researcher to travel back in time to speak to the medical teams, autistics, and non-autistics from the 19th and 20th centuries and thus the best possibility of useful results is to review the literature written in all three centuries. The researcher will then analyse their findings by reviewing, comparing, and contrasting the existing literature (Torraco, 2005), looking for any evidence which gives indications and clues as to whether there is a divide between these two communities and if there is, whether the medical diagnosis or the social construction of autism has in any way contributed to this.

Synthesising the literature, by comparing the different resources and drawing conclusions, allows the researcher to intertwine the tributaries of study together to concentrate on primary issues and resources rather than purely regurgitating the used literature, creating something new from old. This can be seen as the scholarly equivalent to the Kawa Model of reflection (Iwama, 2016). Throughout this whole process the researcher must be highly aware of their own biases as an older autistic in the 21st Century. Whenever a researcher starts their study of choice, their own philosophies, ideas, and prejudices must be taken into account at the very beginning for the sake of transparency and integrity (Smith & Noble, 2014). Throughout the course of constructing the literature review the researcher will identify, analyse, and discuss the types of actual literature used, details of which can be found in Figure 3, on pages 44 and 45 (Table 3), and the bibliography. The researcher will be looking specifically at whether the growing medical diagnosis or the social construction and knowledge had any influence on the autistic and non-autistic communities and if so, how this materialised. As mentioned in the introduction, throughout each of the three main chapters the researcher will first lay out the historical foundation pertaining to the given century utilising historical sources and archive material. The researcher will analyse each of the given literatures looking explicitly for any strengths, key contributions, misconceptions, biases, and links between differing authors. The analysis and synthesis of the literature in this case will be/has been undertaken through close reading and manual cross-referencing for quality, evaluation, and analysis. Themes are identified using keyword and synonym identification, with further contextual markers identified to support this initial evaluation. A compare, contrast and variance blending is undertaken both for accuracy checking and to aid analysis and synthesis. This is then presented via a number of tables synthesising the various themes and sources, with a commentary.

Table 1: Four forms of Synthesis from Integrative Literature Reviews; Adapted from (Torraco, 2005, p. 363

A *research agenda* that flows logically from the critical analysis of the literature. The research agenda should pose provocative questions (or propositions) that give direction for future research (Santos & Horta, 2019).
A *taxonomy or other conceptual classification of constructs* is often developed as a means to classify previous research. They, in turn, lay the foundation for new theorizing (Doty & Glick, 1994). Taxonomy is made up of hierarchical levels, starting with knowledge, comprehension, and application. These are followed by the higher levels of analysis, synthesis, and evaluation (Forehand, 2011)
Alternative models or conceptual frameworks—new ways of thinking about the topic addressed by the integrative review. Alternative models or conceptions proposed by the author should be derived directly from the critical analysis and synthesis provided. Classification and assessments are profoundly interwoven, and their effects are a course intended to both deliver sense and to expediate an enthusiasm to react. (Cohen & Basu, 1987)
Metatheory—The integration and synthesis of a literature review can provide the basis for developing metatheory across theoretical domains through future research. When discussions occur at these metatheoretical arenas, it is the field of conceptual analysis, not empirical investigation. (Witherington, et al., 2018)

The researcher will be primarily reflecting the first form of synthesis outlined in Table 1, as the research agenda flows not only from the critical analysis of the literature, but into the way the material for analysis is chosen.

3.2 Methods and Approaches

Structured summary:

The researcher has decided to use an integrative literature review approach. A literature review amalgamates several assorted scientific studies that all address the same question. The integrative approach allows the layers of literature to inform each other. The benefits of this includes a consolidated review of a larger and sometimes contradictory body of literature (Haidich, 2010).

Context:

Tracking The Timeline Of Perceptions Of Autism In The United Kingdom From The 19th Century To The Current Day

Aim: To find out if the social construction of autism has changed from the 19th Century onwards

Rationale:

Autism has been a largely misunderstood Neurodiversity. Though this piece of research only goes back as far as the 19th Century it is possible to see autism even further back than the Middle Ages.

As we move into the 21st Century more and more is being discovered about this neurological difference. The researcher is researching what, if anything, is changing the societal perspective and knowledge of autism.

The researcher believes this piece of research will help to bring together all the different assets of the autistic condition.

The researcher has looked at other researchers work along similar lines to their own and combined them into a timeline of unique results (Haidich, 2010).

Objectives:

- To understand the evolution of legal acts in terms of the action and reflection of law on societal perception and construction
- To evaluation medical diagnostic approaches and language in terms of the action and reflection of the medical profession on societal perception and construction.
- To analyse dictionary definitions to establish the relationship between language and society in regard to autism.
- To explore the societal relationship between the autistics and neurotypical through a variety of fictional and media representations, including records of audience reception.

Data source:

The researcher chose several different search sources. These were; Google, Google Scholar, Wiley Online Library, Core, the Journal for ReAttach Therapy and Developmental Diversities (Jrtdd), Dimensions. Some of these data sources are specifically medical or centred around autism.

Study selection:

Table 2: Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Directly related to autism and society	Not concerning England
Concerning, or including UK	Not written in English
Qualitative, quantitative or mixed-methods/historical approaches	Concentrating on or dominated by the concept of autism with Learning Difficulties
Peer reviewed or otherwise quality assured (e.g., subject to an editor/editorial board)	

Studies were selected due to their relevance to autism and one or more of the aspects mentioned above shaping the societal perception of autism, including medical diagnosis, legal statute, depictions in fiction and the media. Studies were initially included based on broad search terms as indicated in the table. However, elements of snowballing were also included, whereby the bibliography of one useful text would lead to another and so forth. The researcher is popular in the research community and other researchers also brought texts to the researcher's attention (Frey, 2018). This 'academic networking (King, 2022) or 'collegiality' (Jackson, 2022) is not without problems in terms of repeatability, but it is a well-known technique which most researchers find is brought to them by their academic friends, rather than as a deliberate choice. Bearing in mind the different expertise within each academic circle, the issue lies not with the likelihood of repetition, the method is almost inevitable unless actively excluded, rather it is the likelihood that the resultant resources will be consistent from peer group to peer group that is harder to judge. However, the generosity of one's colleagues should not be lightly dismissed and, it can be argued, informs the integrative nature of this literature review.

In explanation of Table 2, exclusion criteria were set thus:

Texts which did not concentrate, or significantly mention England were largely excluded. They did not have to draw their data exclusively from England, although this was preferred. Initially it was thought that all researchers would be England-based, however this was too restrictive.

A number of self-published texts were excluded. It was deemed that while journalistic and non-academic efforts would not be completely excluded, the writers of these needed to show a significant track record of writing on autism in a field where there is a level of quality assurance, such as use of an editorial board or working for a broadsheet newspaper. It was this criterion that led to, for instance, the inclusion of work by Steve Silberman but excluded the work of Paul Wady. Although Wady's *Guerilla Aspies* is very interesting it has not yet been peer reviewed and is therefore lacking validity in an academic context. The researcher acknowledges that these decisions mean that some areas of interest and relevance may have been excluded.

While not formally an exclusion criterion, the researcher soon became aware of the number of studies written in what appeared to be gratuitously prosaic and inaccessible language (and acknowledges the irony in the presentation of this sentence). Many autistics are also dyslexic, including the researcher, and it was deemed that writing in such a manner not only made the research inaccessible to many autistic researchers, but it also showed a lack of integrity in the stated intentions of many of those writers. One cannot be seen to be promoting understanding *of* the autistic community if one cannot be understood *by* them. This then can be seen to be part of the researcher's axiological stance.

The Inclusion and Exclusion Process.

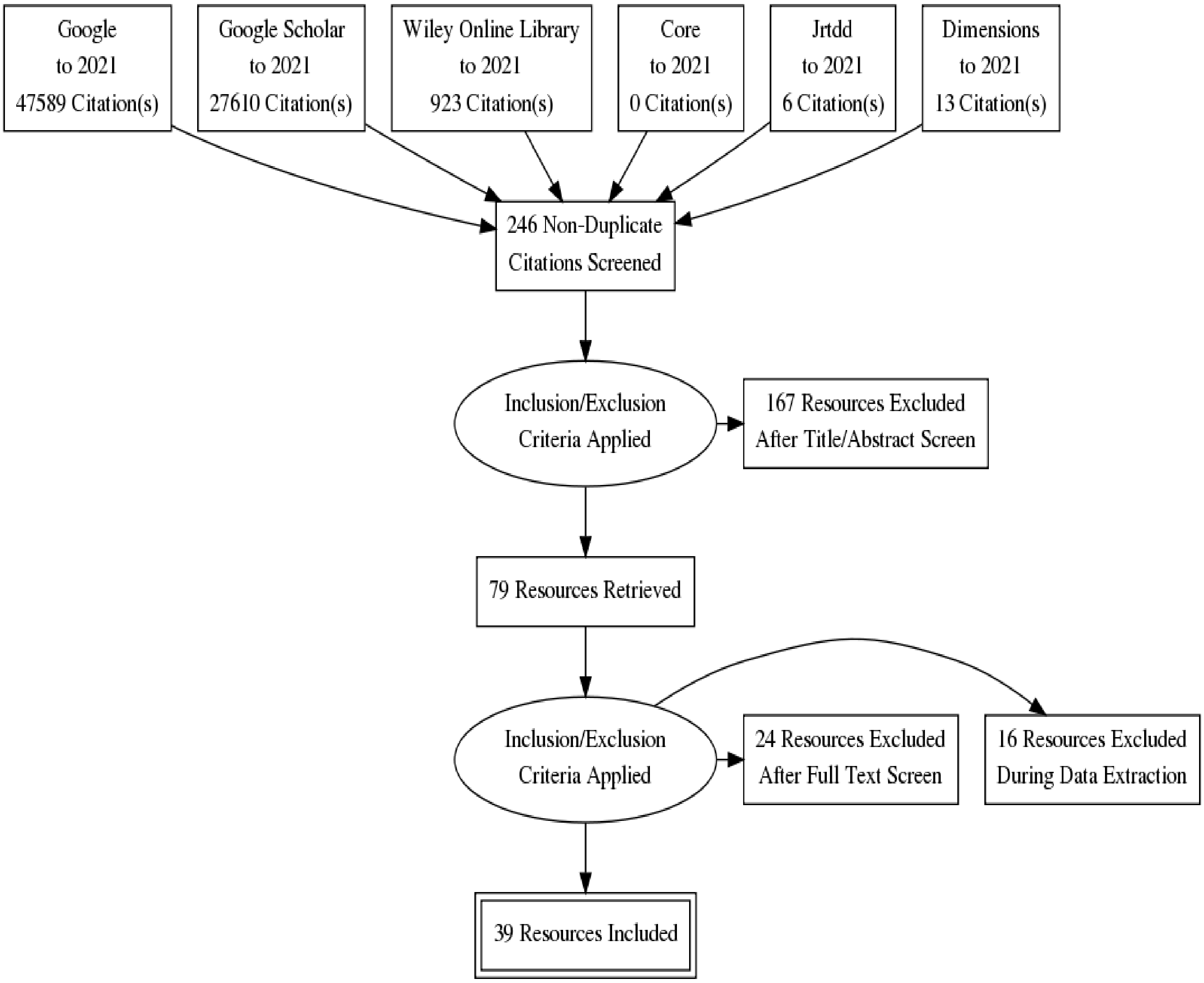


Figure 3: Resource selection process (PRISMA, 2009)

Table 3: Methods and results of literature search techniques

Initial research platforms *			
Google	Google Books	Google Scholar	CCCU Library Search
Leading To:			
Online books and journals	Online books	Online journals	Physical Books
			E-books
Snowballing to:			
		Specialist databases including:	In particular: Silberman, *Neurotribes*
		Online Library. Wiley	This in turn becomes the “seed” text for further snowballing, particularly relevant to Chapter 5.
		Dimensions	
		Core.ac.uk, leading to	
		Jrtdd.com	
*Search Engine keywords and search terms, showing use of Boolean Search algorithm tools			
“Medical diagnosis” AND	Different aspects of autism	Autism “learning difficulties”	Autism NOT “learning difficulties”

autism (about 958,000 hits)			
“Social construction” autism	“19th Century” “medical diagnoses” autism	20th Century” “medical diagnoses” autism	21st Century” “medical diagnoses” autism
“Edward VIII” AND “autistic son”	BNPS “copy of letter” “Edward VIII”		
Though the number of hits is vastly greater than the number actually used this is a proportionate response as not all hits were relevant to the research.			

The researcher has deliberated over whether to use Boolean search terms. Boolean logic conveys the straightforward idea of linking search expressions using the words; AND, OR, NOT (Booth, et al., 2016). Having explored their use the researcher has decided that their efficiency is sporadic and therefore unreliable. The researcher has found that inverted commas do have some benefit but the terms AND, OR, and NOT have minimal effect in expanding or refining the research. The use of inverted commas allows the computer to search for a set phrase rather than 2 separate words, making the search more focussed. The impact of this upon the literature review is that while quite time consuming, the act of searching “by eye” has led to the discovery of literature the Boolean algorithms might have removed from the resources returned. The researcher has therefore used Boolean logic some of the time where necessary but on the whole confines herself to using only the inverted comma aspect to lock the words together.

As mentioned above the researcher has determined to only incorporate literature that refers to the United Kingdom, though it may have been written by a non-British author from anywhere in the world as an exclusion/inclusion criterion. The researcher considered limiting material to only that written since the turn of the 21st Century, but rejected this, so as to increase the chances of using a broader range of material, in and of itself demonstrating evolving situations through language and approach.

As this is an integrative literature review, not a systematic literature review, while a PRISMA approach was the primary technique involved, other methods were not rejected, as will now be explained. The research community is a supportive one and a number of articles were sent to the researcher by interested parties. This then led into a naturalistic approach to snowballing, as hinted in Table 2 above. Snowballing is a simple gathering of data (Sage Publications, 2018), whether that is through word of mouth, following interesting or intriguing leads (as in the references to Edward VIII above, a rare insight into upper-class attitudes) or citation searching, which will be consistently utilised in the following chapters. Snowballing is simply pursuing references of references (Greenhalgh & Peacock, 2005) in the context of a literature review, although there is often a “seed” document (Parker, et al., 2019), or person in the context of participant research. In this instance, the primary seed document was Steve Silberman’s book Neurotribes (Silberman, 2018), which was particularly useful in shaping the 20th Century chapter content. Another example was the first reference to Edward VIII; once found this was snowballed as particularly relevant, as an example of very scant literature around autism in the upper classes during the period. The simple searching of the bibliography or citation lists for further relevant material is a tool that most researchers use and is so commonplace that perhaps it is not commented upon often enough (Booth, et al., 2016).

In all cases, the date parameters of authorship of literature have been left unlimited, to both give as broad a literature response as possible, and to maximise the chances of reflecting changing views throughout the period.

The researcher placed the search term, ‘20th Century medical diagnoses of autism’ into the search engine ‘Dimensions’. This search engine is specifically designed by various science research companies to collect all of their past, present and future research, grants, patents, and clinical trials together onto one platform. Dimensions have also created the whole life cycle of their research, from funding through output to impact (Digital Science & Research Solutions Inc, 2020). Dimensions created a link to the website Wiley. The researcher discovered several helpful journal articles, including, for example, ‘Annual Research Review: Looking back to look forward – changes in the concept of autism and implications for future research’. This will be used later in the 20th Century chapter.

The same search term was then used again in the website Core. Core is a not-for-profit service provided by the Open University. It provides Open Access research papers from around the world for the benefit of researchers, universities, and industry. (Open University, 2020). From Core the researcher was led to the Journal for ReAttached Therapy and Developmental Diversities. This journal is made up of articles submitted by other researchers (ReAttach Therapy International Foundation, 2018). This is where the researcher discovered ‘The History of Autism in the First Half Century of the 20th Century: New and Revised’. This article has the potential to provide valuable information locked within its bibliography.

This process has been reiterated, developed, and utilised throughout this thesis as shown in Figure 3.

Whilst many of these keywords were helpful; they also led the researcher to other literature through the bibliography sections of the discovered literatures.

<u>The researcher used the following Archives online.</u>

National Archives

Langdon Down Museum Archives

Great Ormond Street Archives

It should be noted that the resources found in online archives are included in the sources found in Figure 3. The above archives were consulted as a logical extension of the researcher's pre-existing knowledge. While further archival research would have been desirable, this was curtailed by the combination of Covid-19 restrictions and pragmatic limitations imposed by scope.

Archives Keywords.

19th Century, medical diagnosis of Imbecile and Idiot

The word 'autism' was excluded from all 19th Century archive searches as this condition had not yet been established.

The researcher will critically reflect on the effectiveness of this approach in their Discussion and Findings chapter, and in their conclusion. However, it is worth considering the process of including and excluding material, which is a fairly naturalistic process, but needs to be brought into the conscious mind. Having made the keyword selections outlined in Table 2, the researcher first read abstracts, or extracts, filtering out anything that did not explicitly focus on the United Kingdom and any resources which largely focussed on disabilities and high care needs aspects of autism. Then the researcher either skim read whole articles, chapters and books or using a keyword search, deep read relevant extracts. The researcher's levels of dyslexia led to a pragmatic choice to remove anything with a linguistic that was overly or gratuitously scholastic in tone; not only were these not dyslexia friendly, but in writing in these styles the authors, in the researcher's view, are being exclusionary in their practice. Finally, a deeper and more complete reading was undertaken in order to make final checks ready for sampling and analysis. A visual representation of this process can be found in Figure 3.

Data extraction and synthesis:

Data extraction and synthesis were undertaken through close reading and manual cross-referencing for quality, evaluation, and analysis. Themes were identified using keyword and synonym identification, with further contextual markers identified to support this initial evaluation, a compare, contrast and variance blending was undertaken both for accuracy checking and to aid analysis and synthesis of information. Notes were taken long hand or via audio-recording, allowing analysis to happen organically from the outset. To differentiate between extraction and synthesis, therefore, would be impossible. This was then presented via a number of tables (presented in the appendices) synthesising the various sources, with a commentary presented in the main body of the text.

Conclusion:

At the beginning the researcher's view of the disparity between autistics and non-autistics was laid very much at the door of the non-autistics. Through their exploration there have been many discoveries of deeper knowledge of autism and the development of the dictionary, Acts of Parliament, medical diagnosis, and social construction of this amazing and diverse condition. It has been the combination of all four of these that has led to the slow but encouraging narrowing of the societal gap between autistics and non-autistics in the United Kingdom.

Method

Eligibility criteria:

The researcher focussed on the 19th to 21st Centuries in the United Kingdom. The researcher's selection of authors did not all reside in the UK, though their work was either undertaken from a UK perspective or used widely within the UK. The compositions of the authors had, as a whole, been peer reviewed or quality assured.

Information sources:

The researcher chose several different search sources. These were; Google, Google Scholar, Wiley Online Library, Core, Jrtdd, Dimensions. Some of these data sources are specifically medical or centred around autism.

Search:

An **example** search is presented below:

The researcher used Jrtdd to conduct research on autism by using the keywords ‘Autism’, ‘UK’ and a specific century marker covering the 19th to the 21st centuries. A variety of Boolean markers were experimented with, including AND and NOT, however it was found that only when the use of speech marks was applied systematically was there any optimal search impact.

Jrtdd		
Autism UK 21st century	Autism UK 20th century	Autism UK 19th century
2 hits* focusing on Russia	2 hits, focusing on Dublin, Ireland	Nil return
Dimensions		
3 hits focussing on UK	5 hits focussing on UK, however, discounted as duplicates of those found in previous search	5 hits focussing on UK. However, 4 were replicates of those found in previous 2 searches.
		‘Autism’ ‘UK’ ‘19th century’
		1 hit, brief mention

*the word ‘hits’ refers to raw results, prior to further exclusion and inclusion processes, as reflected in the further comments.

Study selection:

The research community is a generous one. Other researchers who were aware of this study brought resources to this researcher’s attention, often verbally or by sending a link through social media, researcher checked these ‘leads and selected the material to be used independently of influence of friendship or other peer factors. The same is true of any works included via literature snowballing, that is, the checking of reference lists of identified resources for other relevant resources. One of the issues with this, however, is that it can only aid the search for older material, not more recent publications.

Data collection process:

The researcher collated their work based on several factors; the important themes as reflected in the objectives above, corroborated from the analysis of other sources, and their personal and family experience of the autistic condition.

Data items:

There were no areas of data sought with a nil result once all the databases had been consulted. Therefore, all data areas included were in the original selection.

Risk of bias:

The researcher was aware of their own potential risk of bias as they themselves are autistic. The researcher was mindful to extend their work beyond that with which they agree.

An example of this would be in the 20th Century section when the researcher examined Applied Behaviour Analysis (ABA). The researcher's first instinct was to ignore its very existence, so abhorrent does it seem to her, but knew that this would mean an unacceptable gap in the timeline. Through addressing this bias, she was able to discover that, when this was first created and where and when it is still used in its purest form, the research could see the benefits to the autistic person. The researcher's stance sprang from an awareness that this is not always the case and has experienced the devastating effect of this method when used abusively on a family member. Through actively addressing this bias, the researcher was able to present a more balance view on the phenomenon of ABA.

Summary measures:

It was the original intention of the researcher to exclude all autistics with severe learning difficulties. However, within the 19th Century this was impossible as only those with severe learning difficulties were considered by the medical, and political professions, and societal consciousness.

Synthesis of results:

Data synthesis was undertaken, again through close reading and manual cross-referencing for quality, evaluation, and analysis. Quality checks were double checked, these were ensuring all publications were peer reviewed or otherwise quality assured as laid out above. Integrity checks were made, including that the researchers had acknowledged the limitations and parameters of their work. Notes were taken, and due to the researcher’s dyslexia, upon occasion, checking of understanding and synthesis of interpretation was undertaken via informal discussion with colleagues. The final synthesis remains the responsibility of the researcher. The researcher then presented, via a number of tables, the synthesis of the various sources, with a commentary. Throughout this process the researcher used the same terminologies, where possible, across each of the three main chapters.

Risk of bias across studies:

The researcher acknowledged their own risk of bias due to themselves being autistic and coming from a predominantly autistic, wider family. This was mitigated by forcing oneself to examine and include areas such as ABA, provided the studies met the inclusion criteria and the rigour standards outlined above.

Results

Study selection:

As demonstrated in figure 3, all study selection was undertaken manually; no external algorithms or software was used. First all duplicates were eradicated, and therefore discounted the vast majority of the original hits. Next, the exclusion criteria was applied to a scan or skim read and then a close reading of the titles and abstracts, leaving 79 resources. While in effect this was a 2 sub-stage process (1-scan read; 2 – close reading of title/abstract), it is shown in figure 3 above as one stage.

The inclusion and exclusion criteria were then applied to the full texts of the resources. The variety of types of resources meant that this was quite a quick and easy process in some cases, for example, the dictionary definitions, but harder, and a more abstract decision in others. This is the stage where most resources were removed due to the axiological stance of the researcher regarding language, that is that the language used was impenetrable and prosaic to the extreme and was largely the reason for exclusions during data extraction, as the data became unwieldy and unusable.

What remains, applying these stages, is clear and directly relevant to the research aims, open to analysis and synthesis and axiologically in sympathy with the researcher’s positioning.

Study characteristics:

The researcher examined many different articles, books, and websites in the following areas;

Dictionary definitions

Legislation and commentaries on legislation

Diagnostic handbooks and literature related to them.

Commentaries on pieces of fiction and writers

Other socio-political commentaries, biographies, and related texts

Risk of bias within studies:

The researcher is aware that any research being undertaken can lead to researcher bias within the study. Therefore, it is imperative that the researcher looks at all aspects, from all angles, within their research topic.

Results of individual studies:

See appendices 1-3 (Tables 14-19)

Synthesis of results:

Through the synthesis of the data the researcher has been able to establish that there is incongruence between autistics and non-autistics, but the chasm is slowly starting to close. The encouraging influence of self-advocacy by the autistic community and their allies, along with the updating of medical diagnostics and dictionary definitions is resulting in a slow but sure change to the social construction.

The synthetic approach undertaken can be summarised as a thematic exercise done by hand, with no recourse to software such as NVivo, which would have been distracting and time consuming for a researcher with no experience or skills in such areas. The thematic approach was to concentrate on blending and analysing evidence, legislation and ideas that focussed on autistics without learning difficulties. As the period studied moved on, a further theme of community was identified and followed. As the researcher delved further into different areas of literature other topics and themes started to emerge. The researcher then explored these new areas to the point of deciding on their relevance to this thesis, adding or excluding them. An example of this would be whilst undertaking research into the medical diagnoses of autism there appeared the theme of “cures” which the researcher then pursued and subsequently incorporated into this body of work. To apply this example, the researcher identified the Research Autism (2016) resource as relevant to the ABA aspects of theme of “cures”. Quality checks were undertaken as to the credentials of the authors before the data was analysed and synthesised with other quality sources into the information provided on p87-89 of this thesis. While similar information could be sourced elsewhere, the authorial validity of those sources were either doubtful or impossible to establish and were therefor excluded.

Risk of bias across studies:

In the synthesis of the data into results and findings, the researcher continued to hold her own positionality in the front of their thoughts, thus mitigating the risk of unconscious bias as much as one can.

Discussion

Summary of evidence:

Overall, the evidence suggests a gradual narrowing of the chasm between autistics and non-autistics. It points to an acceleration in the closing of this gap as both broader society and the autistic community themselves become more aware of the strengths and opportunities in self-advocacy, fair representation in the media and entertainment. However, new challenges and barriers are emerging in the intersectionality between autism and other minority representations which have yet to be overcome.

Limitations:

This study focussed on; dictionary definitions, Acts of Parliament, medical diagnoses, and social constructionism. It primarily dealt with adult autistics without severe learning difficulties though this was included in the 19th Century due to the lack of recognition of adult autistics with an average IQ or above.

Conclusions:

There are a number of areas where the scope of this project has meant that the researcher has had to curtail their curiosity and activities. All these warrant further research and would make valuable additions to the scholastic resource. They are laid out in detail in the conclusion chapter, but include:

A historic re-framing of Asperger in his role as scientist and his efforts to save some of the children he had diagnosed as having higher IQ's.

As an older autistic who was not diagnosed until in their 60s the researcher would like to promote this inequality and help it to become equal with other age groups.

Though the researcher feels that self-diagnosis is a good first step they also believe that a full medical diagnosis is important. Autism and self-diagnosis is becoming more common due to the prevalence of the World Wide Web and therefore easier access to the criteria of autism.

Though the researcher has no desire to pursue the following area they do still believe that it would be an important area to research: the role of autism in professional creatives, the incidence of LGBTQIA+ and autism, autism in the Victorian age to include both the lower and higher classes, Savantism.

Funding

The researcher secured funding for research travel from the Snowdon Trust. Due to the Covid-19 pandemic hitting the United Kingdom this bought about travel restrictions and therefore was never used.

In this chapter an outline of the methodological standpoints has been undertaken, displaying a broadly integrative approach to the literature review here presented. In particular, the researcher’s use of and appreciation of snowballing from seed sources and its impact on the research has been touched upon. The thesis now turns to the heart of the research.

Literature Review and Findings: 1800 – 1899

4.1 Introduction

For an overview of the number of articles and resources consulted, selection criteria and final numbers included throughout this thesis, see Figure 3 in the methodology chapter above. The literature and resources were selected initially using keyword searches with a variety of Boolean search algorithms, all including reference to the century referenced in the chapter heading. Abstracts or introductions were read for relevance, checking and a further sifting out took place. Relevant factors included country of focus, and the exclusion of all materials concentrating on those with learning difficulties. Finally, a selection was made according to readability.

The literature review has been undertaken based upon the rationale that autism has been, and to an extent, continues to be, a very misunderstood neurodiversity. The literature reviewed demonstrates that the perceptions of autism, both by the neurotypical and the autistic community are changing and developing. The aim of the literature review presented over three chapters is to survey these changes and promote these new understandings. The researcher has explored other researchers work along similar lines to their own and combined them into a timeline of unique results (Haidich, 2010).

The researcher has concluded that in this chapter all resources must be considered within the knowledge that, at this point in time, the term Autism had not yet been created or defined. During the 19th Century there were no formal diagnoses of the autistic spectrum condition. The formation of the diagnosis of autism took place in the early part of the 20th Century and will be discussed in that chapter. The diagnoses available and therefore applied to people in the 19th Century, who in the 21st Century may be diagnosed with autism, included idiocy, imbecility, and lunacy. It then can be argued that therefore society viewed such people as idiots or imbeciles (Waltz & Shattock, 2004). In Edgar Miller's paper 'Idiocy in the 19th Century' he lays out the varied range of terms that may have been used. These include learning disabilities, mental handicapped, mental retardation, idiots, imbeciles, feebleminded, solitaries, morons, aments, fatuity, and cretin (Miller, 1996).

4.2 Dictionary Definitions

The researcher has taken several commonly used 19th Century words, to describe disabled people who in today's setting may be diagnosed with autism. The researcher has considered how these words have evolved over the 19th, 20th and 21st centuries in the chapter Discussion and Findings (chapter 7).

During the 19th Century there were great advances in science and technology which in turn caused language to evolve with new words. These were often taken from the Greek and Latin languages, which can be seen in their definitions (British Library, 2020). Though these terms were acceptable in the 19th Century in today's society they would be deemed to be discriminatory.

Set out in Appendix 1 and the Discussion and Findings chapter are the definitions, as understood in the 19th Century regardless of when that definition originated, as taken from the Online Etymology Dictionary (Harper, 2020).

The researcher notes that as early as the 20th Century the meanings of these words had started to change to be more offensive to the general population. These words, in the main, are not used within society in the 21st Century, and their dictionary definitions have greatly altered compared to the previous two centuries.

4.3 Acts of Parliament - Great Britain

Prior to discussing the bulk of the literature pertaining to legislation in the 19th Century, it is worth taking a moment to introduce this central theme across the whole thesis. In the three chapters, 19th, 20th, and 21st Centuries, the researcher has looked at the Acts of Parliament in the United Kingdom relevant to the criteria of autism within those centuries even though the term autism is not specifically mentioned along with other medical terminology. The researcher will then compare how they evolved in the Discussion and Findings chapter.

The purpose of an Act of Parliament in the United Kingdom is to create a new law or to change an existing law. It has to be approved by both the House of Commons and the House of Lords and then has to be given Royal Assent by the Monarch. An Act can later be repealed if its provisions are no longer applicable, this can be done by a Parliamentary Committee (UK Parliament, 2020c).

British Home Secretaries of the 1820s and 1830s had a languidly dismissive way with those who wrote to complain about the English lunacy laws. Scrawled on to the back of these letters and petitions were instructions to Home Office administrative staff on how to deal with such a communication: “No answer, he is half crazy himself”; “Point out to him that the mere fact of such an application having been made casts a serious doubt upon the soundness of the gentleman’s mind”; “Nil—Mad”’ (The Lancet, 2014). This implies that British Home Secretaries were applying the terms in a casual way even though they may not have had diagnostic training or the medical credentials to do so.

Set out in Appendix 2 and the Discussion and Findings chapter is a table summarising the Acts of Parliament as understood in the 19th Century.

Many of the Acts deal with facilities for paupers and lunatics. St Peter's Hospital was one such establishment, built in the centre of the city of Bristol in 1698, and functioning as a multi-purpose institution with separate accommodation for lunatics and idiots. Even though the city centre was not an ideal location. During 1823 the Bristol authorities designated it as a County Lunatic Asylum. In 1845 the Home Office and Commissioners in Lunacy demanded it was replaced with a new borough asylum outside the city. It took several years of resistance by Bristol authorities before this was actioned (Smith, 2017).

Many of these Acts provided the basis for building mental hospitals and asylums away from cities. The rationale of removing the mentally challenged people with learning difficulties away from the general population reflects the societal construction of not wanting them within their community within that period.

The researcher has discussed further in the Discussion and Findings chapter (chapter 7) below how at first the Acts were undertaken with good intentions though they might have been open to abuse and manipulation.

In conclusion, the researcher discovered that the Acts of Parliament were multi-faceted, and very long in the 19th Century, reflecting a naïve understanding of the conditions to which they applied. The researchers ponders if this would have made it much harder to apply to any one given instance.

4.4 Medical Diagnoses:

4.4.1 19th Century IQ

In the early days of diagnostic explorations into what is now recognised as autism, it was often the presence of some form of learning disability that prompted the medical profession to examine patients' intellectual ability. Therefor the discussion of IQ is relevant to this research into the perception of autism.

During the 1890s, while examining the conception of intelligence which would highlight the difference between clever and unintelligent children, Binet highlighted the different kinds of mental processes by which human beings differ. This in itself made categorising extremely difficult (Harwood, 1983); Binet's was one of many IQ systems begun around this time however Binet did not succeed in fully developing an IQ test until the early 20th Century. "However, can we measure the richness of inspiration, the accuracy of judgement, the ingenuity of the mind?" (Eckberg, cited in Harwood, 1983).

Set out in Appendix 3 and the Discussion and Findings chapter is a table summarising the Medical Diagnoses as understood in the 19th Century.

Dr William Howship Dickinson (1832–1913) (Historic Hospital Admission Records Project, 2010), was one of the founders of Great Ormond Street Hospital. Dickenson was educated at Cambridge, elected honorary fellow at St Georges Hospital, graduating in 1859, becoming an assistant physician in 1866 and physician in 1874. (Brown, 2019). Dickinson volunteered at Great Ormond Street Hospital in London, founded in February 1852, from 1861 to 1874. Dickinson was known for his keen sense of observation of children, both in their behaviour and brain function. He hand wrote three volumes of case notes, concerning 398 children. Waltz & Shattock (2004) claim that 24 of these correlate to the present day diagnosis of autism (Dickinson, 1869-1882). Seven out of these 24 were admitted to Great Ormond Street purely because of their autistic symptoms (Waltz & Shattock, 2004).

In the journal article "Autistic Disorder in Nineteenth Century London" there are three case reports concerning children admitted to Great Ormond Street Hospital. One of these cases is that of a young boy called George admitted in September 1877. George had difficulty as a baby, feeding, sitting, standing, and walking unaided. George also had not developed normal speech but used different sounds and gestures to communicate. George showed little interest in the things around him, nor did he retain eye contact. He made repetitive arm and leg movements consistent with stereotypical arm and hand flapping. Dr Dickinson labelled George's symptoms as dementia. No drug treatment or improvement is mentioned in his case files. It has been observed in recent years that George's symptoms meet the DSM-IV criteria for autistic disorder (Waltz & Shattock, 2004)

The researcher initially viewed the Great Ormond Street hospital's archives online concerning Dickinson's diagnosis of the twenty-four children correlating to today's understanding of Autism. The researcher then contacted the archivist, Nick Baldwin, with a view to examining these documents. After looking through approximately 300 documents the researcher was only able to isolate 12 cases that the researcher perceived to be in line with the 21st Century diagnostic view of autism. For example: lack of eye contact, non-verbal, intestinal distress, sensory abnormalities, and lack of emotional regulation. Though the researcher would have preferred to have re-examined these specific documents in more depth, due to Covid-19 restrictions the archives were closed, making this impossible.

At almost the same time as Dickinson's work, Dr John Langdon Down was making similar discoveries. Dr John Langdon Down (1828-1896) left his family business at the age of eighteen to train as a pharmacist, graduating in 1848. Later he went on to study as a medical student at the London Hospital where he excelled and was awarded many of their medical medals. He went on the become a member of the Royal College of Surgeons in 1856. His career in medicine continued to develop throughout his lifetime (Langdon Down Museum, 2013). Langdon took over the failing Earlswood Asylum for Idiots which had been founded in 1852. One of his first tasks was to ensure all residents could use a knife and fork. The anonymous author of *Nature* (1873), in responding to an address by Dr J.C Bucknill which mentions this, theorises that it is pointless to take pleasure in learning that idiots are being shown how to use a knives and fork, when normal people do not have access to knives and forks and would not want them (Scientific Serials, 1873). The researcher hypothesises that during that period, it was deemed more important that the general populace were given access to societal norms rather than those who were deemed disabled.

Langdon Down continued to change the way the hospital was run and how the residence were treated including training into trades. Langdon Down spoke at the Lettsomain lectures on the subject of Idiots Savants. He explained how this name was given to children who were otherwise known as feebleminded, though the researcher's reading of the traits and behaviours he described would now be recognised as common signs of a diagnosis of autism, exhibiting special facilities. For example, Langdown Down described a youth who could build model ships from drawings and had great carving skills yet was unable to cut up his own food. There was another boy who could read books and remember and quote back every single word, and yet another young child who was able to give the name and address of every sweetshop in London, as well as the dates of every one of his visits. Langdon Down also observed that these traits were not just connected with words but also numbers. One child of about 12 years old could multiply any three figures by three figures with perfect accuracy and speed yet could not remember the doctor's name. He also observed that in every case of idiot savants none of the children's parents, brothers or sisters had the same ability. Surprisingly, Langdon Down had never met a female with this condition (Langdon Down, 1887).

Langdon Down used IQ as his diagnostic technique, defining idiocy as having an IQ of less than 20 and imbecility as having an IQ of 21 and over. (Langdon Down Museum of Learning Disability, 2020a). Mark Rapley, in his book, *The Social Construction of Intellectual Disability*, quotes Edgerton, Lloyd and Cole as saying that historically an idiot was someone with an IQ of less than 30, an imbecile had an IQ of 30 to 50, and a moron and IQ of 50 to 70 (Rapley, 2004). The researcher wishes to draw the reader's attention to just these IQ tests only being applied to autistic children with severe learning difficulties and not to those autistics without. In the 19th Century it is unlikely that autistics without severe learning difficulties would have been medically diagnosed, as outlined at the beginning of this chapter. Thus, these are a hidden population for whom there is very little reliable data. There is a deeper conversation about IQ tests both for people on the autistic spectrum and for neurotypicals, but the researcher has decided not to pursue this at the present time due to issues of scale. Rapley (2004) also defined idiocy into three categories; Congenital; before, after, or during birth. Developmental; after birth. Accidental; illness or shock after birth. Langdon Down later resigned his post at the Earlswood Asylum and along with his wife, Mary, set up Normansfield in Teddington, London. This was a private asylum for mentally handicapped children from the upper classes and those from a 'good social position'. They felt that these children where often hidden away from society. Normansfield opened in 1868 with a south wing being added in 1869 and a north wing added 1873, with more land and properties being added as the asylum expanded. In the 1980s Normansfield was under the control of Richmond, Twickenham, and Roehampton Healthcare NHS Trust, finally closing in 1997 (Lost Hospitals of London, 2020).

Maudsley contributed £30,000 for the establishment of a hospital for the 'early treatment of curable mental illnesses and for research and teaching in psychiatry' (Turner, 1988). Maudsley Hospital opened in 1923 for the purpose of undertaking mental health care, teaching and research (NHS South London and Maudsley, 2022). The Maudsley Hospital still provides assessments and treatments for both children and adults in the 21st Century. The researcher themselves were diagnosed through this institution.

The researcher concludes that the 19th Century was an exciting time for the development of medical diagnosis across a wide spectrum of conditions, including what we would recognise today is autism. However, diagnosis at this point was a relatively blunt instrument, more likely to focus on the learning disability aspects of what we now consider to be autism with learning disabilities, and unlikely to recognise the true nature of autism for those without learning disabilities.

4.5 Social Constructionism

In the early part of the 19th Century only the wealthy could afford to have their children educated, the class difference was more visible, as were the economic and work structures of the United Kingdom. By 1869 the National Education league had been formed. Their first campaign was to instigate free, compulsory, and non-religious education for all children; this led to the 1870 Education Act (UK Parliament, 2020a). Travel was also limited across the country and therefore the social construction from area to area, which was mainly verbal, took a lot longer to spread. The growth of train travel and increasingly accessible fares had a gradual speeding up impact on this as the century progressed. Both these factors have an influence on how society constructed views on a societal sector. In introducing compulsory primary education, the 1870 Education Act (UK Parliament, 2020a) and the legislation that followed, put children who had not had opportunities to mix together previously into the same classroom. Potentially this also meant that teachers were exposed to children with conditions and backgrounds they had never encountered before either. As in all areas of society, the advent and increased speed of travel via trains led to a better distribution and dispersal of knowledge about autism as newspapers, medical textbooks and other resources could be transported more quickly, effectively, and cheaply around the country. As people began to travel more, they encountered more people from different sectors of society, including those who were neurologically different from themselves. This all led to the opening up of the social construction of autism in the 19th Century.

“Some boys laugh at poor cripples when they see them in the street”, observed a religious advice pamphlet for children in 1848. “Sometimes we meet a man with only one eye, or one arm, or one leg, or who has a humpback. How ought we to feel when we see them? We ought to pity them”. The pamphlet then went on to tell the jeering boys that the cripple would be made “bright and beautiful” on Judgement Day by God. However, the wicked able-bodied children who laughed at the cripples would be “burned in a fire that will never be put out”. This was very much the Victorian view on disability, combining divine judgement with fear, pity, and discomfort (Jarrett, 2012). There was, in essence, a parent-child relationship between the 19th Century classes. The ruling classes considered themselves fathers to the working classes. The “fathers” provided shelter, food, and other needs, whilst the “child” showed respect, deference, and labour (McDonagh, 2006). This is referred to as Victorian paternalism and reflects much of the 19th Century attitude towards those perceived as less fortunate, including those with mental and physical disabilities and mental health issues.

In Raymond Williams' book *Keywords* (Williams, 1983), he equates equality to the social as well as the physical sense in the 19th Century. Therefore, men are often unequal in their height, muscle tone, colour of their skin and so forth, but in law they are or at least should be equal, though this is not always the case, nor in the case of power over other men or woman. It is in this approach to equality, rather than equity, (this will be covered in more depth in the 21st Century chapter) that can be found many of the issues in the socially constructed gap between autistics and non-autistics, particularly in the 19th Century. Williams argues that these inequalities are rooted economically, and this can perhaps be seen in how we might now consider how autistic are described. As seen in the dictionary definitions, many words have judgements attached to them about their moral or economic worth.

It was not until the 19th Century that people with intellectual impairments were included in fiction, unlike people who were labeled with "idiocy" in earlier literature (Dickinson, 2000). Writers, including Dickens, began to both reflect and challenge the Victorian paternalism that had rapidly become the status quo, as demonstrated above (McDonagh, 2006). In particular, the main character in Barnaby Rudge showed strong signs of autism; diminished intellect, impaired socialisation, irrational fears, and poor communication (Douglas, 2008). An example is as follows.

"he, old and elfin-like in face, but ever dear to her, gazing at her with a wild and vacant eye, and crooning some uncouth song, as she sat by and rocked him; every circumstance of his infancy as came thronging back, and the most trivial, perhaps the most distinctly. His older childhood, too; the strange imaginings he had; his terror of certain sense-less things-familiar objects he endowed with life;" (Dickens, 1998).

In Julia Rodas' article, “On the Spectrum”: Rereading Contact and Affect in Jane Eyre, she suggests that Jane Eyre “is an individual on the autistic spectrum” (Rodas, 2008).

Mark Rapley quotes Edgerton, Lloyd, and Cole (1979). ‘It is practicable to refer to two basic types: clinical and sociocultural. Clinical retardation can usually be shown to have concomitant organic deficits of a neurological, metabolic, or physiological sort. In sociocultural retardation, such children are most likely to have been born to parents who are economically, socially, and educationally disadvantaged' (Rapley, 2004). This can be extended into the field of societal attitudes towards autism, a neurological condition, throughout the period examined here and continuing into the 21st Century.

4.5.1 Autistic “Cures”

The word “cures” can also be interspersed with the word “treatment” though for simplicity throughout the whole of this thesis the researcher will refer only to the word “cures” to cover both terminologies.

The researcher, as an autistic from a highly populated autistic family, along with many other autistic people, finds the concept of “cures” offensive and has therefore used speech marks to illustrate and acknowledge that bias. As the medical fraternity has become more and more obsessed with “curing” autistic people this has filtered through to the wider social community, including autistics themselves, though as discussed in the 21st Century chapter this is now starting to change. Therefore, the researcher chose to include the discussion of “cures” within social construction rather than medical diagnoses.

Whilst in Great Ormond Street hospital the children who displayed what today might be diagnosed as autism received very little medical care, though those with severe bowel complaints would have been treated with Senna syrup, calomel (mercury chloride), and cod liver oil, and of course they also received respite from the poverty that they lived in (Waltz & Shattock, 2004).

The researcher acknowledges that there were many changes within society throughout the 19th century including in the area of education for all children and within the societal demand for “cures” for autistics.

4.6 Conclusion

Though the word autism (taken from the Greek word “autos” meaning self, describing a person removed from social interaction (WebMD, 2019) had not yet been created in the 19th Century, the researcher, through examining archival information, established that, though under a different name, autism was in existence. The people with this condition were referred to by multiple dictionaries defined words, many of which would no longer be used today. During this time there were multiple Acts of Parliament, covering the reflected views of the day. When looking at the medical diagnosis of autism very little practical help was given to these people at that time. It also became clear that in the majority of cases, people in the 19th Century who were recognised to have this condition would also have had learning difficulties. The researcher, on considering all these factors together, surmises they would have created the social construction of how these people were viewed, spoken about, and treated.

Literature Review and Findings – 1900 – 1999

5.1 Introduction

The 20th Century is often thought of as a significant game changer for autistic people and autism was often thought of as the 20th Century disorder (O'Reilly, et al., 2019).

During the 20th Century, linguistics, meanings, and medical diagnosis started to develop into what we would recognise today in the 21st Century. Eugen Bleuler used the term autism in 1908 during his clinical work on Schizophrenia, stating that it was a whole group of four 'A's; loosening of Associations, disturbances of Affectivity, Ambivalence, and Autism. (Fusar-Poli & Politi, 2008). Significant steps were taken in recognising and understanding the condition, critical thinking, and the political issues of the inclusion agenda (O'Reilly, et al., 2019). There was also a move by the autistic community themselves to own this condition as normal. This, along with other areas of disability activism, created a range of movements, critical psychiatry, neurodiversity, consumerism, and social models of disability (O'Reilly, et al., 2019). Aspects of this will be discussed throughout this chapter.

5.2 Dictionary Definitions

The words in this section of the Dictionary Definitions are taken from the familiar words in the 19th Century chapter above. These will be analysed, to see if or how the meanings have changed, later in the Discussion and Findings chapter.

Set out in Appendix 1 and the Discussion and Findings chapter are the definitions, as understood in the 20th Century, taken from The Concise Oxford Dictionary of Current English (Fowler & Fowler, 1919).

As stated in the previous chapter, the dictionary definitions had started to change and develop throughout the 20th Century. This was caused primarily by the change to medical diagnosis and society being able to mix and therefore communicate amongst themselves more easily.

5.3 Acts of Parliament: Great Britain

In the early part of the 20th Century the House of Lords had the power to stop legislation. This changed in 1911 to the House of Lords only having the ability to delay a bill for up to 2 years, this was reduced to one year in 1949 (UK Parliament, 2020b). This switches the balance of power from the hereditary elite to the elected commoners and arguably, led to the beginning of the end of paternalism. This began what has grown to be a more reflective House, including greater representation by the end of the 20th Century of the rights and concerns of autistic people and other minority groups.

Set out in Appendix 2 and the Discussion and Findings chapter is a table summarising the Acts of Parliament as understood in the 20th Century.

The 1913 Mental Deficiency Act mentioned in table 8 defined four grades of Mental Defective. In each case the condition had to be present "from birth or from an early age" (Meanwood Park Hospital, 2020). There was a slight amendment in 1927 to allow the inclusion of those who were exhibiting destructive and anti-social behaviours as a remnant of recovery from the encephalitis lethargica pandemic.

1. idiots were people "so deeply defective in mind as to be unable to guard against common physical dangers"

2. imbeciles were not idiots but were "incapable of managing themselves or their affairs, or, in the case of children, of being taught to do so."

3. feeble-minded people were neither idiots nor imbeciles, but: If adults, their condition was "so pronounced that they require care, supervision, and control for their own protection or the protection of others"; if children of school age, their condition was "so pronounced that they by reason of such defectiveness appear to be personally incapable of receiving proper benefit from instruction in ordinary schools".

4. moral defectives were people who, from an early age, displayed "some permanent mental defect coupled with strong vicious or criminal propensities on which punishment had little or no effect"

(Meanwood Park Hospital, 2020).

This is the first evidence that disability and morality are linked in law and diagnosis which will be considered more closely in the Discussion and Findings chapter.

The researcher acknowledges that throughout the 20th Century the Acts of Parliament were starting to become more concise and specific concerning people with any form of disability including autism.

5.4 Medical Diagnosis:

5.4.1 20th Century IQ

Deficiency and defect are not distinguished (see table below) Both imply a lack of something. The below classifications are here compared to the analysis of mental retardation in the International Classification of Diseases (9th revision - 1975): Mental retardation is defined as intellectual impairment starting in early childhood.

Within the ICD-10 Classification of Mental and Behavioural Disorders 1992 it is stated that though all levels of IQ can be found within those on the autistic spectrum, there is a significant mental retardation in three-quarters of autistics (World Health Organisation, 1992).

Jack Tizard (1919-1979) was a research psychologist, Professor of Child Development, Research Unit Director, an international adviser on learning disability and childcare, and a President of the British Psychological Society. He researched the average IQ of 'feebleminded' people who were detained across 12 hospitals to be 70. This, at the time was credited to be the upper limit of an intellectual disability (Clarke, 2005).

The Court of Protection of England and Wales (CoP) made financial and welfare decisions for people presumed not capable of doing this for themselves (Weston, 2020). The CoP came under much scrutiny in the 20th Century, later changing to the Mental Capacity Act in 2005 (Mencap, 2021)

There is a strong link between IQ as an indicator of legal status and the expectation of how a person might be treated by society, this is true across all humans. The diagnostic tools which might lead to medical treatments and interventions for autistics are discussed below.

Set out in Appendix 3 and the Discussion and Findings chapter is a table summarising Medical Diagnoses as understood in the 20th Century

Table 3: IQ classifications (adapted from Roberts, 1981)

Classification of Intellectual Impairment	**IQ Range**	**Synonyms**
Mild Mental Retardation	50 to 70	feeble-minded, moron, high grade defect, and mild mental sub normality
Moderate mental retardation	35 to 49	imbecile; moderate mental sub normality
Severe mental retardation	20 to 34	severe mental sub normality
Profound mental retardation	Under 20	idiocy; profound mental sub normality

The percentage of autism diagnosis rose significantly in the later part of the 20th Century due to the closure of many institutions for ‘mentally retarded’ children, and parents demanding enhanced diagnosis and recognition of their children’s problems (Evans, 2013). Jack Tizard was one of the first to study whether adults with severe learning difficulties had the potential to learn. He also evaluated the effects of removing severely disabled children and adults out of institutions, this was called the Brooklands Experiment. He later collaborated with Albert Kushlink to set up community services and small residential units to replace institutions (Clarke, 2005).

Though there is no specific date given for when this took place, such groups as UK Society for Autistic Children, founded in 1962, advocated for new treatments methods. This society later changed their name to the National Autistic Society (National Autistic Society, 2018). Evans (2017) theorises that the growing increase of diagnosis of autism is actually down to the progress that psychiatry of children has developed through the 20th Century, in particular in the United Kingdom between the 1960s and the 1990s.

Dr Hans Asperger. (1906-1980) a Viennese clinician identified four young children who were exceptional in the areas of maths and science, though their relationship with others, including their parents, was sparse. Asperger referred to them as ‘little professors’ and their condition as autism (Silberman, 2016). Asperger also believed that autism was primarily a male condition (Wired, 2020). Asperger was not the only person to believe in this phenomenon, it is also stated within the 1992 ICD-10, F84.5 (World Health Organisation, 1992). In this modern day his name has been refuted as more and more evidence of Asperger’s involvement in the Nazi-controlled Vienna comes to light (Czech, 2018). Asperger was at one time thought of as one of the pioneers of autism diagnosis and became the namesake of Asperger's Syndrome. "It is said he helped many with the syndrome to survive by telling the Nazi authorities that people with autism could be useful to the state because of their unusual and useful abilities" (Langdon Down Museum of Learning Disability, 2020).

DSM-IV included Asperger's syndrome as dissimilar from autism. People with Asperger's were considered to be more intelligent than those who were autistic (O'Reilly, et al., 2019a). This misconception continues to this day.

The works of Kanner and Asperger were reviewed by two British specialists who created the title of autistic spectrum disorder. There were three main categories that were used in clinical discussion;

1. Impairments in social interaction
2. Impairments in communication
3. Restrictive repetitive patterns of behaviour.

(O'Reilly, et al., 2019a).

Asperger's syndrome was not recognised until the 1990's and was removed from DSM-4 in 2013 along with PDD and other well-known autistic conditions. All variants of autism now come under the one title of autistic spectrum disorder (O'Reilly, et al., 2019a). Despite this 2013 change, the researcher wishes it to be noted that in 2018 they were medically diagnosed with PDD-NOS even though that diagnosis was no longer recognised under DSM-5.

Hamburger, a close friend of Asperger, conscripted Erwin Jekelius, who later became answerable for the deaths of thousands of psychiatric patients and mentally disabled children. Jekelius continued at the clinic from 1933 to 1936, devoting part of this time to the Heilpädagogik ward (Czech, 2018).

Lorna Wing, (1928-2014) and Judith Gould (born 1956) founded the National Autistic Society. Wing originated the term Autism Spectrum, completely overhauling the thinking around autism. In the 1970's, along with Dr Judith Gould, they discovered the numbers of people with autism had been very underestimated. Taking the estimated one in 10,000 to one in 100. Wing also set up the first diagnosis centre at the National Autistic Society, founded in 1991. It was known as the Diagnostic Centre for Social and Communication Disorders but was later renamed the Lorna Wing Centre for Autism in 2008 (National Autistic Society, 2018a).

Kanner became aware around 1938 of marked differences between children under the age of 11. In his journal article, Autistic Disturbances of Affective Contact, he gives examples of eleven of his case studies he undertook (eight boys and three girls). Kanner concludes that these children show differences from the then usual diagnosis of schizophrenia. He goes on to muse that further study of these children would be effective and at this point he calls the condition "inborn autistic disturbances of affective contact" (Kanner, 1943).

In 1956 Wing gave birth to a daughter who was autistic. Back then the presumption was that children were potentially normal but could not be educated because they had unfeeling, over intellectual parents. Through Wings maternal experiences she, along with her husband, wrote their first book on autism (1966). Wing wrote a further book 'Autistic Children, A Guide for Parents' in 1971. Later in 1996 she revised this book, renaming it 'The Autistic Spectrum'. During the 1960s Wing executed comprehensive research into the similarities between autism and other disabilities. These included

Downs Syndrome, Aphasia, Blind and Deaf Children, and the Typically Developing Child. She discovered that the autistic person experienced other disabilities associated within the other groups, and therefore concluded that autism is a spectrum (Gould, 2015).

Between the 1960s and 70s a significant shift occurred in the meaning of the term ‘autism’. Before this time autism was referred to as ‘having excessive hallucinations and fantasies’ whereas by the mid-1960s Michael Rutter, a researcher from the Maudsley Hospital in London, conducted the first ever genetic study resulting in the contradictory meaning of autism as in containing a deficiency of fantasy rather than an overabundance (Rutter, 1972).

Handicap International was founded in 1982 by two French doctors, taking its name from the French word for disability. In more recent times this name has been changed to Humanity and Inclusion, reflecting the change in how disabilities are now described. Handicap International had its first centres in the refugee camps of Thailand, Cambodia, Burma, and Laos and covered a wide range of disabilities. In 1992 they joined forces with five other organisations to setup the International Campaign to Ban Landmines. This amalgamated into the mine Ban Treaty in 1997 (Humanity & Inclusion, 2022).

In the middle of the 20th Century the World Health Organisation (WHO) instructed their Mental Health Programme to actively investigate improving the diagnostic classification of mental disorders, this was also to include autism (World Health Organisation, 1992). Within this document, autism is referred to in terms of deviance with some degree of developmental delay (World Health Organisation, 1992).

ICD (International Statistical Classification of Diseases and Related Health Problems) and DSM (Diagnostic and Statistical Manual) laid out the criteria for diagnosis of autism. Within these are the foundation for diagnostic tools such as DISCO (diagnostic interview for social and communication disorders), ADI-R (autism diagnostic interview-revised), ADOS (autism diagnostic observation schedule), 3Di (developmental, dimensional, and diagnostic interview) (National Autistic Society, 2020a).

DISCO; a timetable for the identification of the autistic spectrum and associated conditions and appraisals. DISCO can be used for all ages and levels of ability, therefore helping the clinicians to identify specific features for each individual (Wing, et al., 2002).

ADI-R delivers a systematic evaluation of individuals suspected of exhibiting any of the autism spectrum disorders. This is comprised of ninety-three factors concentrating on three main areas:

1) language and communication
2) reciprocal social interactions
3) restricted, repetitive, and stereotyped behaviours and interests
   (Rutter, et al., 2022).

ADOS; prearranged assessments of social interaction, communication, play, and imaginative use of materials for persons suspected of having the autism spectrum disorder. This comprises of four 30 minute components determined by the client’s level of communicative language (Lord, et al., 2000).

3Di; This process is computerised and is utilised for administration by trained interviewers who generate symptom and diagnostic profiles for both autistic and non-autistic conditions. The results are used to ascertain whether any of the symptoms and diagnostic profiles are in fact common in both cohorts (Skuse, et al., 2004).

The creation of DSM-5 was started at the end of the 20th Century. It was the first time a DSM had been given a number rather than a Roman numeral. This new DSM caused much debate and was subject to public examination because of the development of the World Wide Web (O'Reilly, et al., 2019).

The *Diagnostic and Statistical Manual of Mental Disorders (DSM–5)* has taken over ten years of effort by a large number of international experts on all areas of mental health. This is now used to classify mental disorders, to improve treatment, research, and diagnoses across the world (American Psychiatric Association, 2020). In examining the various editions of the DSM, one can track the evolution of autism diagnosis since the 1980s.

DSM-III; APA, 1980 listed child autism as a standalone diagnosis for the first time. It used one of the six criteria, ‘Pervasive lack of responsiveness to other people’ (Happe & Frith, 2020).

Stated in the ‘Brief Report: Interrater Reliability of Clinical Diagnosis and DSM-IV Criteria for Autistic Disorder: Results of the DSM-IV Autism Field Trial’, historically the diagnosis of autism has been the most reliable. Though there has been some controversy with inexperienced physicians not understanding the broad range of symptoms and categories (Klin, et al., 2000).

DSM-5 APA, 2013 however refers to ‘Autism Spectrum Disorder’ as ‘Persistent deficits in social communication and social interaction across multiple contexts…’ (Happe & Frith, 2020).

For decades it was thought that there were only three to four children per ten thousand with autism. In the late 20th Century this greatly increased, and there was concern that there was an epidemic of unknown source (Silberman, 2016). One of the first autism frequency approximation, by Lotter (1966), was also in the region of 4 in 10,000. Wing, who established the conception of the ‘autism spectrum’, gave an estimation of 22 in 10,000 from her epidemiological analysis of children known to special educational needs facilities in Camberwell (Wing & Gould,1979). Similarly, in the 1980s, autism was deemed to be a very infrequent disorder. In recent times, the median of commonness approximations of ASD (a term now changed to ADC) worldwide was given as 62 in 10,000 (Elsabbagh et al., 2012). A broad estimate of 1 in 100 is widely accepted today, with some assessments being greater (All estimates cited in Happe and Frith 2020) (Happe & Frith, 2020).

In 1998 the Lancet medical journal published a research paper by Andrew Wakefield that prompted the Measles Mumps and Rubella (MMR) scare. The Lancet subsequently withdrew and discredited the article. Wakefield carried out unnecessary and invasive tests on children without ethical approval, conflict of interest and the appropriate qualifications. Wakefield was involved in a lawsuit concerning several of the children in his study, trying to prove there was a link between the MMR vaccine and the children’s autism. Multiple, high quality research studies have gone on to show that the MMR vaccine is completely safe and not linked to autism. In 2003 the World Health Organisation, after conduction extensive reviews, stated that there is no evidence to suggest the MMR vaccine causes autism (NHS, 2010).

During the 20th century there was a rise within pharmacology and psychiatry to identify and manage autism. There was also more critical vocabulary, political philosophies, questions, along with a range of factions such as critical psychiatry, anti-psychiatry, consumerism, neurodiversity, and social models of disability (O'Reilly, et al., 2019).

In conclusion the researcher draws the attention to the new term autism that was created in the early 20th Century along with the DSM diagnostic manuals later in the 20th Century. This had a major impact on the autistic community as well as society as a whole. The researcher believes that the 20th Century was one of the most important times for autistic people in terms of diagnostic advances.

5.5 Social Constructionism:

As autism was being given its name, society started to look at not just autistics with learning difficulties but also identifying those without. The way autism was being spoken about also changed, this included within politics as well as in the new movements emerging such as neurodiversity, consumerism, and societies models of disability. Society within itself was trying to reinvent what autism meant, not just to the autistic person but to society itself (O'Reilly, et al., 2019). In the late 20th Century, with the invention of the World Wide Web, social media has permitted extensive communication across the world. This has given a weightier voice to marginalised communities to express how they view themselves and their desire on how to be treated by others. There are several examples of how significant people are now being viewed within the realms of autism.

Alan Turing (1912-1954) was a brilliant mathematician, founder of computer science, World War II codebreaker, theoretical biologist, and philosopher. Turing created the theoretical plan for computers to be programable, helped design computers themselves, designed the Automatic Computing Engines to be built by the UK Government and wrote many papers including on Artificial Intelligence (Turing Trust, 2020). Though it is commonly accepted that Turing was homosexual, there is also a train of thought that he may have also been autistic. Jon Brock, in his research blog, looks at some of the hypotheses over whether Turing may or may not have been autistic (Brock, 2012). He cites O'Connell and Fitzgerald's (2003) findings after studying Turing's biography. They used the Gillberg criteria for Asperger syndrome and concluded that Turing met all six of the criteria; Severe impairment in reciprocal social interaction, all-absorbing narrow interest, impositions of routines and interests (on self or other), nonverbal communication problems, speech and language problems, motor clumsiness (BBB Autism Online Support Network, 2020). Brock then concludes that some of these criteria are being stretched a little too far as evidence, for example his high-pitched voice and working late into the night. As with all historical diagnoses it is difficult to be completely accurate. This is especially true covering the parameters of autism were, as Lorna Wing put it, Asperger syndrome "shades into eccentric normality" (Brock, 2012). Therefor this researcher concludes that it is highly probably that Turing was a non-medically diagnosed autistic.

In Sarah Turing's book about her son, Alan Turing, she lays out some of his characteristics. As this section involves discussion of family members with the same surname, here the academic tradition will be broken, and the key players will be referred to by their first names. Here are some examples: he would toss his head back with a jerk flicking his hair. He took little interest or care about his clothes and what he was wearing. He could retreat into his shell (Turing, 2012). In this same book Alan's brother, John Turing, surmises about Alan's death. Alan died by taking cyanide which was found to be on an apple. It is said that Alan was obsessed with the story of Snow White and that he ate an apple every day at bedtime. In the story of Snow White, she is given an apple laced with cyanide which causes her to fall into a deep sleep only to be awakened by a handsome prince. There has been some hypothesis that maybe Alan laced his night-time apple with cyanide hoping that he too would be awakened by a handsome prince (Turing, 2012). Of course, this is largely conjecture, but indications can be interpreted strongly.

Max Ferreira on his website ‘exposure’ hypothesises that Hans Christian Anderson and Lewis Carroll may both have been autistic. In particular, he cites Hans Christian Anderson’s book ‘Ugly Duckling’ as a manifestation of Anderson’s own autistic traits. Anderson himself defines his renowned story as a reflection of his own life (Ferreira, 2021).

Born in 1979, Travis Meeks described himself as an introvert who struggled to make friends. But he found solace and inspiration in music. Like many children with autism, obtaining a diagnosis had many challenges. His early years comprised of misdiagnosis after misdiagnosis (ADD, bi-polar, paranoia disorder), he was finally diagnosed with Asperger’s Syndrome in 2005. All these misdiagnoses led to him feeling extreme shame, exhibiting behavioural problems, and an addiction to drugs. The turning point for him was in the 1990s with the creation of the ‘grunge scene’ and his first single (AppliedBehaviourAnalysisEdu.org, 2021a).

Satoshi Tajiri, the famous inventor of Pokémon was born in 1965 and openly admits to being autistic. As a child he was fascinated by insects and was given the nickname “Dr Bug” (Applied Behaviour Analysis, 2021b). Tajiri was also obsessed with computer games, often missing classes at his high school. At seventeen he started writing and editing a fan magazine which focused on the arcade game scene called Game Freak. This is one of the companies that make Pokémon games. Tajiri joined up with Ken

Sugimori and after studying coding language created their own game company in 1989 (Eldred-Cohen, 2011-2020).

A series of books by Chris Bonnello called Underdogs were first released in 2019. These novels were about a group of teenagers attending a special school becoming the final hope of freeing the British people who had been imprisoned in walled citadels. These teenagers go from being underdogs to becoming heroes. The author, Chris Bonnello is himself autistic, having been assessed at the age of four in 1989 but being deemed as not being severe enough he did not receive his full diagnosis until the age of 25. Bonnello has also become a national and international speaker on autism issues encouraging others to define themselves by their strengths rather than their weaknesses. These books are supported by Steve Silberman the author of Neurotribes (Bonnello, 2022).

In 2009 Professor Simon Baron-Cohen warned against parental testing for autism and the creation of a prenatal drug treatment as this creates the possibility that society may lose certain talents like numerical abilities, "*An ability to understand numbers could be in DNA"* (Baron-Cohen, 2009).

Michael Oliver, in his introduction of his 1990 book, *Critical Texts in Social Work and the Welfare State the Politics of Disablement*, expresses his opinion that disabilities have had little profile in academic circles and have mainly featured with any importance in medicine or psychology. Oliver recommends that other disciplines such as sociology, anthropology, history, politics, and social administration take the area of disability seriously (Oliver, 1990).

In the early 1900s the main idea in the general population was that people with autism had three main characteristics; impairments in social development, (inappropriate use of eye contact and a failure to develop close relationships with others, particularly a failure to develop friendships), communication, (never developed speech, while others do develop speech but experience problems with the pragmatics and social aspects of language), and the display of rigid and repetitive behaviours (hand flapping, ritualized behaviours and an overly focused interest in a particular topic or object) (Brownlow, 2010) Any human can be thought as “disabled‘ because of how the perceptions of his or her difference are viewed within a society. Differences are not understood as an individualistic attribute but created through social constructionism (Brownlow, 2010).

Neurodiversity is a word created by Judy Singer in the late 1990s. Singer was herself autistic and used this word to collate things like autism, ADHD, dyslexia, and other related conditions. In her interview with Andrew Solomon in 2008 she expressed her desire to do for the neurologically different people what feminism and gay rights had done for their communities (Silberman, 2018).

In an outline of a presentation, primarily addressed to parents of autistic children, given by Jim Sinclair (1993) he speculated that the parents’ grief for the autistic child is much more an expression of the parents’ grief for themselves at producing a child with disabilities. He goes on to say that autism is not something a person has, or a shell that that person is trapped within, he says there is no normal child hidden away. He talks about autism existing as a way of being, inescapable, it colours everyday understandings, every sensation, observation, contemplation, emotion, encounter, in fact every aspect of existence. Further, it is not possible to separate the autism from the person and that in fact if you could, you would be left with someone totally changed from who you began with (Sinclair, 1993). The researcher themselves agrees with

Sinclair's observation. As an autistic person the researcher would not be who they are today, with all their quirks and idiosyncrasies, with their ability to think outside the box, and their obsession with serving others, had they not been born with the gift of autism.

However, autism has not always been viewed this way; the news website for the 'Mirror' ran an article on the discovery of a letter written by Edward VIII concerning Prince John (White, 2015). This letter was discovered in an old trunk by a stamp collector and later sold at the Julian Auctions for £20000. Prince John was diagnosed with epilepsy and autism at the age of four and died at thirteen in 1919, having spent his later years hidden away in Sandringham. It is said that King George did not want anyone to think the Royal blood was tainted. The following is quoted from the Open University "In the 20th Century, the British Royal Family hid away some of its members who had disabilities" (Williams, 2005).

5.5.1 Autistic "Cures"

In 1930, Julian Huxley, secretary of the London Zoological Society and chairman of the Eugenics Society wrote: "What are we going to do? Every defective man, woman and child is a burden. Every defective is an extra body for the nation to feed and clothe but produces little or nothing in return." Eugenics was a popular theory and social movement around the world in the early 20th Century (Historic England, 2020).

Figure 4: Brochure for the 1932 International Conference of Eugenics (Historic England, 2020)

Nikolaas Tinbergen, a man famous for his work on gulls and sticklebacks, along with his wife applied ethological theory to the condition of autism. (The British Journal of Psychiatry, 1983) They theorised that autism was the result of the derailment of the social development of a child possibly caused by some distressing experience. They believed that the child’s anxiety levels escalated to the point where the child could no longer overcome them and this created a fear of social situations and new experiences, known as approach-avoidance conflicts. The Tinbergens believed that this phenomenon was because of the stress caused by modern civilisation. They also hypothesised that the associated epileptic fits were just an extension of temper tantrums, and this in turn led to intellectual retardation. They did not believe, that in the majority of cases, there were any physical abnormalities of the brain and therefore autism was curable. Consequently their “cure” involved the child’s mother holding the child until the child relaxed and returned the cuddles. The Tinbergen’s claimed success but without any objective evidence, defining their criteria of improvement or “cure”, or any long-term follow-up studies (The British Journal of Psychiatry, 1983).

The researcher discovered that there is a great deal of literature concerning Applied Behaviour Analysis (ABA) being used on autistic children and has therefore decided to look at the root of this therapy.

Burrhus Frederic Skinner followed in the footsteps of John B Watson (1878-1958) a psychologist who established the psychological school of behaviorism through his work on animal behaviour and child-rearing (GoodReads, 2020). Though Skinner’s views were a little less extreme than Watson’s, believing that humans have minds, he focused primarily on observable behaviours rather than internal mental events. Skinner’s understanding of behaviour was by looking at the cause of an action and its consequences. He called this ‘Operant Conditioning’, though this was based on the work of Thorndike (1905). Thorndike studied learning in animals (usually cats) using a puzzle box to test the ‘Law of Effect’ (McLeod, 2018). Skinner added reinforcement to the Law of Effect believing that behaviour which is reinforced is then repeated. Skinner identified three types of responses that follow behaviour; neutral opulence, reinforces, punishes (McLeod, 1988).

Dr. Lovaas developed Discrete Trial Training (DTT), in the nineteen seventies in America. He worked with autistic children who also had learning difficulties including mutism. His main area was in using ABA with non-verbal autistic children. He later discovered that children who live with their parents, and therefore ABA was reinforced, fared much better than the children in institutions who often went back to being non-verbal once ABA was discontinued (Research Autism, 2016). Though ABA is about positive reinforcement for desired behaviours it would seem that Lovaas's DTT also advocated punishments which include electric shocks (Child Mind Institute, 2020).

The science of behaviour stems back to the early 20th Century. It is based on the premise that to improve the human condition, behaviour must change. Scientists have conducted thousands of studies to identify the laws surrounding behaviour (Institute of Epidemiology and Health Care, 2021). They have looked at if behaviour is predictable or learned and how it has changed over time. ABA has been extensively used to change socially unacceptable behaviours. This research though has majored on its use with autistic people (BACB, 2020). Parental led advocacy groups started to emerge in the 20th Century leading to more children being diagnosed with autism (Evans, 2013). Some of these groups openly disagreed with the use of ABA, though not all. Some parents advocated its use as a way to "cure" their child.

The researcher also noted that throughout the latter part of the 20th Century, there was a growing phenomenon of attention placed on whether significant scientists and other key figures may have been autistic, and therefore open to claiming by the autistic community as one of their own. There was also an increase in literature pertaining to autism and the search for a "cure" throughout the 20th Century.

5.6 Conclusion

Very early in the 20th Century the term autism came into existence having been created by Eugen Bleuler. It can be seen that gradually the dictionary definitions having previously been used started to change and even in a few cases disappear altogether. Likewise, the Acts of Parliament were also being narrowed down into more contracted headings. The way that autistic people were being diagnosed was developing into the specifics of the autistic condition. As autism became more widely known about within society the societal construction changed. Though this was a slow process with society still viewing autistics as having learning difficulties.

Literature Review and Findings: 2000 – 2021

6.1 Introduction

As we are only in the early years of the 21st Century the researcher will understandably not cover the whole of this century. Certain observations can be made however, how medical diagnoses and law has developed, and the increased use of social media which has triggered the perception and evolution of autism to greatly speeded up.

Autism is still one of many differences in the world that in the 21st Century are slowly starting to level up with the general population.

As with the 19th and 20th Century the researcher will continue in the same format.

6.2 Dictionary Definitions

The researcher is aware that we are only in the first 20 years of the 21st Century and therefore these definitions may change as the century progresses. Even though there are limited definitions or those presented are now deemed old fashioned and offensive, the researcher will still analyse them in the chapter Discussion and Findings along with the 19th and 20th definitions.

Set out in Appendix 1 and the Discussion and Findings chapter are the 21st Century definitions as taken from the Oxford Dictionary (Oxford Advanced Learner's Dictionary, 2020).

Many of these terms have now moved from the formal to the informal, from official to offensive. Many of the words used in the 19th Century are now no longer used amongst the general population of the United Kingdom. The researcher will speak of this again in more depth in the Discussion and Findings chapter (chapter 7).

6.3 Acts of Parliament - Great Britain

In the 21st Century the House of Lords is mainly made up of life peers across a vast field of experiences: academia, business, science, and medicine, reflecting a recognition of the need for expertise from all walks of life in the House, rather than simply a Hereditary entitlement. There is also a greater range of diversity, these include women, ethnic and religious minorities, and those with disabilities (UK Parliament, 2020).

Set out in Appendix 2 and the Discussion and Findings chapter is a table summarising the Acts of Parliament as understood in the 21st Century.

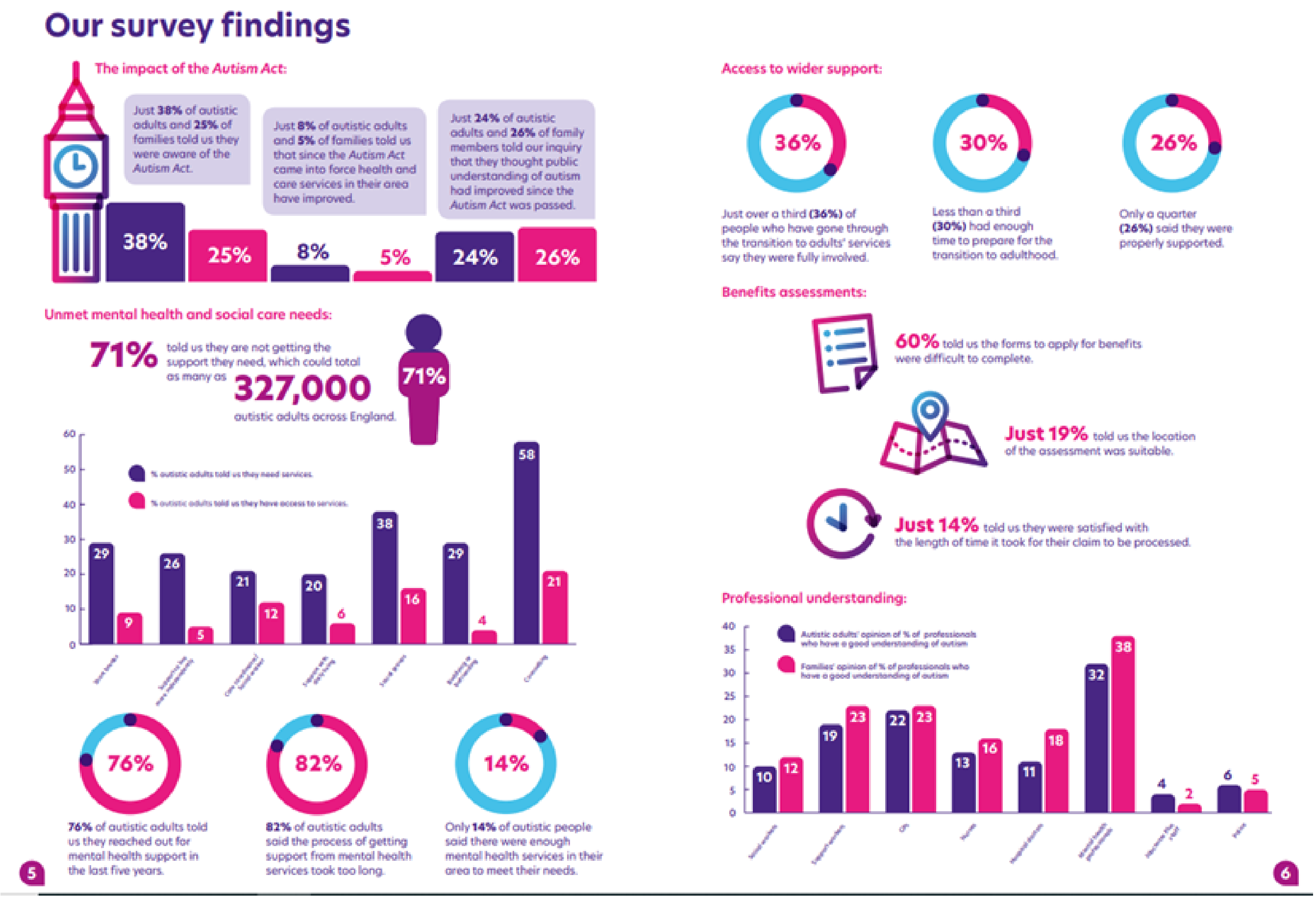
The Autism Act 2009 is the first and only condition-specific legislation of its kind in England. The original Adult Autism Strategy, *Fulfilling and Rewarding Lives,* was published in 2010. In April 2014 this was updated by, *Think Autism.* This gives guidance to local authorities, along with NHS bodies concerning exercise, respectively, social care and health services. In 2014 the Children and Families Act was put in place to support young people prepare for adulthood. In the same year along there was the creation of the Care Act, to specifically help to prevent and delay the need for care and support (Lamb, 2015).

Below are the opening comments from the Secretary of State, The Rt Hon Sajid Javid, for Health and Social Care, as written in the policy paper; *The national strategy for autistic children, young people, and adults: 2021 to 2026*. Updated 22 July 2021

> As a society, we've come a long way since the landmark 2009 Autism Act.
>
> We've never had a greater public awareness of hidden disabilities like autism.

> That awareness is increasingly reflected in how our country is run, from the NHS to local government services.
>
> Although we’ve come so far over the last decade, there must be no limit to the ambitions of autistic people; they should have the same opportunities as everyone else in society.
>
> For me, our goal must be nothing less than making sure autistic people from all backgrounds, ethnicities, genders, sexualities, and ages – in all parts of the country – get the support they need to live full and happy lives.
>
> (Gov.UK, 2021a).

The Autism Act, 10 Years On:



Our survey findings

The impact of the *Autism Act*:

Just **38%** of autistic adults and **25%** of families told us they were aware of the *Autism Act*.

Just **8%** of autistic adults and **5%** of families told us that since the *Autism Act* came into force health and care services in their area have improved.

Just **24%** of autistic adults and **26%** of family members told our inquiry that they thought public understanding of autism had improved since the *Autism Act* was passed.

Unmet mental health and social care needs:

71% told us they are not getting the support they need, which could total as many as 327,000 autistic adults across England.

76% of autistic adults told us they reached out for mental health support in the last five years.

82% of autistic adults said the process of getting support from mental health services took too long.

Only **14%** of autistic people said there were enough mental health services in their area to meet their needs.

Access to wider support:

Just over a third **(36%)** of people who have gone through the transition to adults' services say they were fully involved.

Less than a third **(30%)** had enough time to prepare for the transition to adulthood.

Only a quarter **(26%)** said they were properly supported.

Benefits assessments:

60% told us the forms to apply for benefits were difficult to complete.

Just 19% told us the location of the assessment was suitable.

Just 14% told us they were satisfied with the length of time it took for their claim to be processed.

Professional understanding:

(National Autistic Society, 2019a).

The government of the United Kingdom called for a review of the Mental Health Act 1983 in 2017. This proposed review was published in January 2021. The consultation finished on the 21st of April 2021. There are four main principles being proposed.

1) Choice and autonomy – This is to allow those who are receiving care to be listened to by mental health staff.

2) Least restrictions - The people being cared for should only be kept in hospital if they really need to be there.

3) Therapeutic benefit - The care that is being received should be targeted, resulting in the person recovering more quickly leading to their speedier release from hospital.

4) The person as an individual - care should be fair and targeted for each individual person.

(Gov.UK, 2021)

The National Autistic Society are predicting that if this review of the Mental Health Act is made into law, which may still take several years, then fewer autistic people could be sent to mental health hospitals. They go on to point out that autism is not a mental health problem and therefore autistic people should never have been or be sectioned (National Autistic Society, 2021). In 2019 the National Autistic Society launched a petition which gained 217,828 signatures, asking the government to desist with placing autistic people in mental health hospitals (National Autistic Society, 2021).

The researcher discovered that the many Acts of Parliament within the 19th Century had now been honed down into a much shorter list. Prominence is now placed on the Mental Health Act which is in the process of being reformed with the hope that autism will be removed.

6.4 Medical Diagnosis:

6.4.1 21st Century IQ

A definition of a Mental Disorder is a syndrome characterized by clinically significant disturbance in an individual’s cognition, emotion regulation, or behaviour that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress or disability in social, occupational, or other important activities. An expectable or culturally approved response to a common stressor or loss, such as the death of a loved one, is not a mental disorder. Socially deviant behaviour (e.g., political, religious, or sexual) and conflicts that are primarily between the individual and society are not mental disorders unless the deviance or conflict results from a dysfunction in the individual, as described above' (American Psychiatric Association, 2012-2013).

Set out in Appendix 3 and the Discussion and Findings chapter is a table summarising the Medical Diagnoses as understood in the 21st Century.

Table 4: 21st Century IQ classifications (adapted from Sattler, 2008)

IQ Classification	**IQ Range ("deviation IQ")**
Low average	80-89
Borderline impaired or delayed	70-79
Mildly impaired or delayed	55-69
Moderately impaired or delayed	40-54

The researcher discovered that there was little change from the 20th to the 21st Century definitions of IQ. However, within the 21st Century it has now become common knowledge that autistics are not just categorised with having low IQs but have a very diverse range.

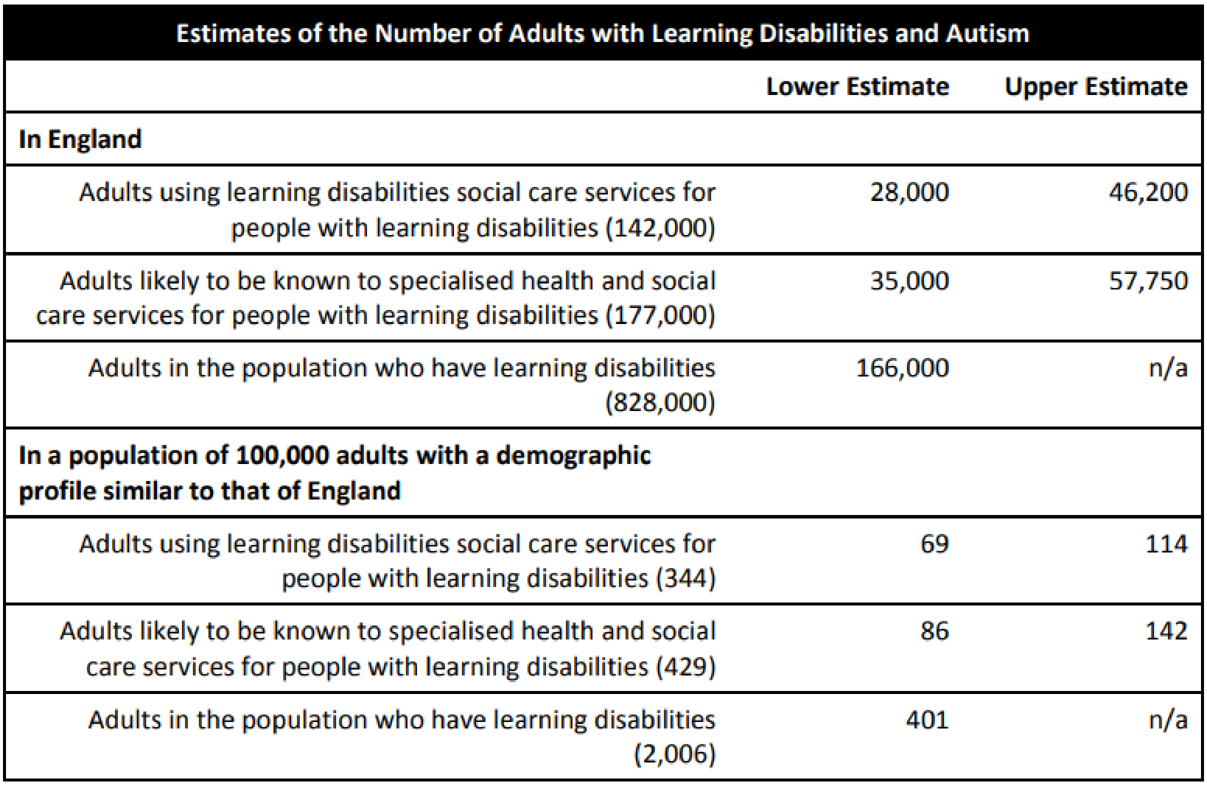
During the 21st Century many changes have taken place in the medical diagnosis of autism, including diagnosing older people and more woman (Lai & Baron-Cohen, 2015). It is estimated that 1 in 100 are on the autistic spectrum, but only 21.7% are in any form of paid employment (Beyond Autism, 2021). One of the many difficulties for an older person to acquire a medical diagnosis of autism is a questionnaire they need to have completed by someone who knew them as a child. For a lot of older people this is not possible as their parents, siblings or childhood friends may have passed away (Beyond Autism, 2021a).

Taken from the National Autistic Society webpage, *What proportion of autistic people have a learning disability?*

“Between 44% - 52% of autistic people may have a learning disability.

Between 48% - 56% of autistic people do not have a learning disability”.

(National Autistic Society , 2018).



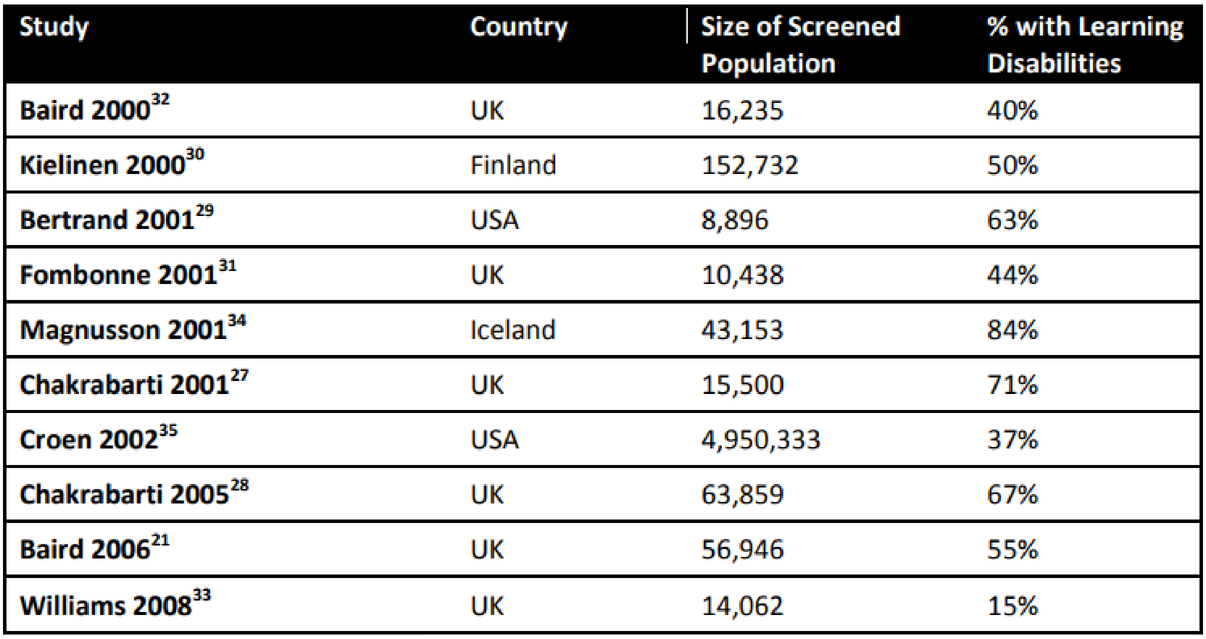
Estimates of the Number of Adults with Learning Disabilities and Autism

	Lower Estimate	**Upper Estimate**
In England		
Adults using learning disabilities social care services for people with learning disabilities (142,000)	28,000	46,200
Adults likely to be known to specialised health and social care services for people with learning disabilities (177,000)	35,000	57,750
Adults in the population who have learning disabilities (828,000)	166,000	n/a
In a population of 100,000 adults with a demographic profile similar to that of England		
Adults using learning disabilities social care services for people with learning disabilities (344)	69	114
Adults likely to be known to specialised health and social care services for people with learning disabilities (429)	86	142
Adults in the population who have learning disabilities (2,006)	401	n/a

Figure 5: Estimates of the Number of Adults with Learning Disabilities and Autism (Emerson and Baines, 2010)

The researcher was unable to find any more up to date information. It is approximated that 20% to 33% of adults with autism who are known to Councils with Social Services responsibilities also have learning disabilities. Throughout England, this implies that between 35,000 and 58,000 adults, who are probable users of social care services, have both autism and learning disabilities. The number of grownups in the populace who have both autism and learning disabilities (counting those who do not use specialised social care services) is probably much higher. There are four factors to be taken into consideration: age, ethnicity, social economics and an autistic with learning difficulties and people with learning difficulties and not autism (Emerson & Baines, 2010).

The prevalence of autism in children varies from the upper estimate of 150 per 10,000 to the lower estimate of 100 per 10,000. The estimate of children with autism who also have learning disabilities ranges from 15-84%.



Study	Country	Size of Screened Population	% with Learning Disabilities
Baird 2000[32]	UK	16,235	40%
Kielinen 2000[30]	Finland	152,732	50%
Bertrand 2001[29]	USA	8,896	63%
Fombonne 2001[31]	UK	10,438	44%
Magnusson 2001[34]	Iceland	43,153	84%
Chakrabarti 2001[27]	UK	15,500	71%
Croen 2002[35]	USA	4,950,333	37%
Chakrabarti 2005[28]	UK	63,859	67%
Baird 2006[21]	UK	56,946	55%
Williams 2008[33]	UK	14,062	15%

Figure 6: Prevalence of autism in children by country (Emerson and Baines, 2010)

Public Health England guidance for learning disability states that; ‘Individuals regardless of their age, gender or label should receive care that is based on their unique needs, that is appropriate in its design and effective in its delivery' (Public Health England, 2018).

In 2018 the Global Handicap International Network became known as Humanity & Inclusion or in some countries as Handicap International. HI (Humanity & Inclusion) is a foundation operating in over sixty countries, including the UK. Amongst their many focuses they are giving disabled people more adequate access to education, rehabilitation, and psychological support (Humanity & Inclusion, 2022).

Williams asserts in his book, *Learning Disability Policy and Practice*: *Changing Lives?* that society is starting to realise that all people should be recognised as contributing citizens and have any of the existing policies helped in achieving this (Williams, 2013).

Bulluss and Sesterka researched the impact of late diagnosis on older autistic people. They exposed that delayed diagnosis of autism in adulthood can change self-concept for the better. Although these people were aware of their differences, and compensated for them, they did not understand why they were different (Bulluss & Sesterka, 2020).

The University of Cambridge is conducting a research project to test if markers showing in an 2D ultrasound of a pregnant woman, twenty-five to thirty weeks gestation, can predict aspects of behaviour in infancy and toddlers associated with autism. This project has no aim to terminate any of the pregnancies (Dr Allison, et al., 2022).

The researcher, in their Discussion and Findings chapter looked at how some United Kingdom Doctors are implementing a ‘do not resuscitate’ order on all autistic’s with Covid-19.

According to the House of Commons library briefing there are over 1.2 million people in England with a learning difficulty. The government is working with the National Health Service (NHS) in England to try and reduce the inequalities between ND (neurodiverse) and NT (neurotypical) people. This is set out in the government's mandate to the NHS 2018-19 (Parkin et al., 2020).

Extensive tests were carried out on 708 verbal (as opposed to selectively mute) autistic young people to ascertain whether the DSM-V testing had been an effective model (William, 2012). These tests were carried out in the United States, but the results are being used by the NHS in the United Kingdom.

Volkmar and McPartland discuss how Kanner described what he called early infantile autism and how over the past two decades changes have occurred in how the condition is conceptualised (Volkmar & McPartland, 2014). They suggest that the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders, 4th edition (DSM-IV), DSM-5 and the World Health Organization's International Classification of Diseases and Related Health Problems, also used in the United Kingdom NHS, must strike a careful balance between being too broad or too narrow. There is a need to equalise the clinical versus research (Volkmar & McPartland, 2014). In January 2022 the World Health Organisation (WHO) will be releasing the latest up-to-date ICD-11 (World Health Organisation, 2021).

The National Autistic Society's website displays three of the main diagnostic tools that are used within the UK. Diagnostic Interview for Social and Communication Disorders (DISCO). Autism Diagnostic Observation Schedule (ADOS). Autism Diagnostic Interview-Revised (ADI-R). Further details of these diagnostic tools can be found at https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-tools/all-audiences (National Autistic Society, 2022).

Happé, Ronald & Plomin (2006) in their article, “Time To Give Up On A Single Explanation For Autism”, ask the question, should the three widely recognised diagnostic criteria; impaired social interaction, impaired communication and restricted and repetitive interests and activities, be looked at more individually rather than as a linking triad (Happe, et al., 2006).

The National Autistic Society list many of the terms that are currently used towards autistic people. These include autistic spectrum disorder (ASD), autistic spectrum condition (ASC) (much preferred by a majority of autistic people), classic autism Kanner autism, pervasive developmental disorder (PDD), high-functioning autism (HFA), Asperger syndrome, and pathological demand avoidance (PDA). They also point out that some autistic people also have learning disabilities, mental health issues or other conditions (National Autistic Society, 2016).

The researcher concludes that within the 21st Century, medical diagnoses has advanced considerably. Some of this can be equated to the advancement of technology but also by the demand of people who suspect either their children or themselves may be on the autistic spectrum.

6.5 Social Constructionism:

The social construction of autism has changed vastly over the last three centuries. However, even in today’s world the attitude among many is to attach a moral viewpoint, such as that a child or young person is behaving this way due to poor parenting or neglect, and that undiagnosed adults are somehow morally lacking, lazy or inattentive because they cannot make eye contact, or communicate in the typical ways expected of them (Strong, 2020).

A study undertaken by Boddison and Soan in 2021 concludes that the English education structure is at a significant place in relation to the role within the SEND policy and needs urgent revision. The Government of England is seeking to enable equity of opportunity to both parents and educational professionals to requests for an Education, Health and Care (EHC) assessment. Currently there is a wide gap between the success of a parental request and an educational professional's request to acquire an EHC, with the educational professionals being much more likely to succeed (Boddison & Soam, 2021)

It was not until 2001 that to discriminate against higher education students became illegal in the UK, though there is still vast discrimination in universities as compared to other sectors (McLeod et al., 2018).

The University of Birmingham undertook a peer-to-peer project to better understand the needs of the autistic student and any barriers that they experienced. This enabled the autistic student to have a meaningful voice in their educational experience. The project permitted the development of recommendations for both students and staff, and the development of a model of peer-to-peer meetings. The AuVision project (AuVision, 2022) was also developed to be replicated to cover not just autistics but those with other disabilities across a higher education environment (McLeod et al., 2018).

Today the societal constructs travel fast around the world due to the increasing access to media coverage and the World Wide Web. One example of this would be in the comparison of how the gay community took on the task of becoming publicly visual in the mid-to late 20th Century. Now in the 21st Century the same phenomena are taking place with the autistic community. As with the gay community going public there are merits and risks to coming out as autistic (Price, 2020). The researcher can testify to this in their own life. Before coming out as autistic they were perceived as “a little odd”, but once they had come out as autistic they were then perceived as “disabled”.

Natalia Lyckowski, Global Neurodiversity Advancement Leader at IBM, has written an article about *‘What is the correct label to use to talk about neurodivergents’?* She quotes from a poll taken by NDs *“33% said YES I identify as disabled, 33% said Absolutely Not and the other 33% said "It depends on what I'm trying to get".* Lyckowski then makes a very valid point, asking why autistic people should have to produce a doctor’s letter to say that they need to be able to sit in a quiet environment, and yet others can automatically get a break to pray or pump breastmilk (Lyckowski, 2022).

One hundred and eight adults with autism were asked to monitor their social media interaction and self-report. Seventy-nine point six individuals (averaged figures) used social networking sites for their social interactions. Those who did this reported that this was where they had their closest friendships. The use of social media on its own was not associated with lower levels of loneliness (Mazurek, 2013).

6.5.1 Autistic “Cures”

The researcher continues their earlier research into ABA into the next century and other ‘cures’.

In 2005 Bob and Suzanne Wright created Autism Speaks, advocating Applied Behaviour Analysis (ABA) as a ‘cure’ for Autism. With the help of Bernie Marcus who helped them set up with a yearly donation of $5 million over five years. (Autism Speaks, 2019) Philanthropist Bernie Marcus also has his own research and treatment foundation for Autism (Ferguson, 2012). ABA has three fundamental steps, antecedent, the resulting behaviour, and the consequences. The first step is about the command or request. The second stage is the resulting behaviour, correct or incorrect. The third step, consequences, is dependent on the outcome of the second stage. If the resulting behaviour is in line with the command or request then a reward is given, however, if the resulting behaviour is not in line with the command or request then no reward is given (Autism Speaks, 2019a). Those autistics who support autistic self-advocacy do not agree that ABA has any curative aims and they believe that it is a physical harmful treatment which if used on non-autistics would be labelled torture (WE. SPEAK Autism Friends Network, 2013).

In the 21st Century there is a marked increase in human to robot interactions (Shamsuddin, et al., 2012). The following report is taken from an engineering article from Malaysia. These robots are now being used to interact with children on the autistic spectrum. The areas being targeted are communication, socialisation, and playful behaviour. The initial interaction with the robot is showing results of suppressing the child's autistic behaviour during the child to robot interactions. It has also been observed that the autistic child makes better eye contact with the robot than they do with their teacher (Shamsuddin, et al., 2012). This tells us that even in these modern, progressive days, medical and technical scientist are still trying to "cure" autistics of their incurable condition, which many autistics themselves do not desire to be "cured" of.

"Neurodiversity is an essential form of human diversity. The idea that there is one "normal" or "healthy" type of brain or mind or one "right" style of neurocognitive functioning, is no more valid than the idea that there is one "normal" or "right" gender, race or culture” (Walker, 2020). Further views on neurodiversity have been expressed thus: Saba Salman interviewed Simon Baron-Cohen on ‘Neurodiversity the next frontier, but we are failing autistic people’ (Salman, 2019). “All different types of brains are normal, but greater understanding has not led to more money for autism” says world-leading expert Dr Damian Milton (University of Kent) in *The Neurodiversity Reader* (Milton, 2020). The Neurodiversity Movement celebrate autism, seeing it as ’other’ and not as a disability. Even within the autistic community itself there are different constructions on whether autism is a disability to be ‘cured’ or a condition to be embraced (Costandi, 2016). In an interview for the NewScientist, Anna Remington director of Centre for Research in Autism Education (CRAE) at University College London, hypothesises that autism has been examined incorrectly. She states that our understanding of ASC has been distorted by the medical presumption that autism is an impairment rather than a diversity (Wilson, 2018).

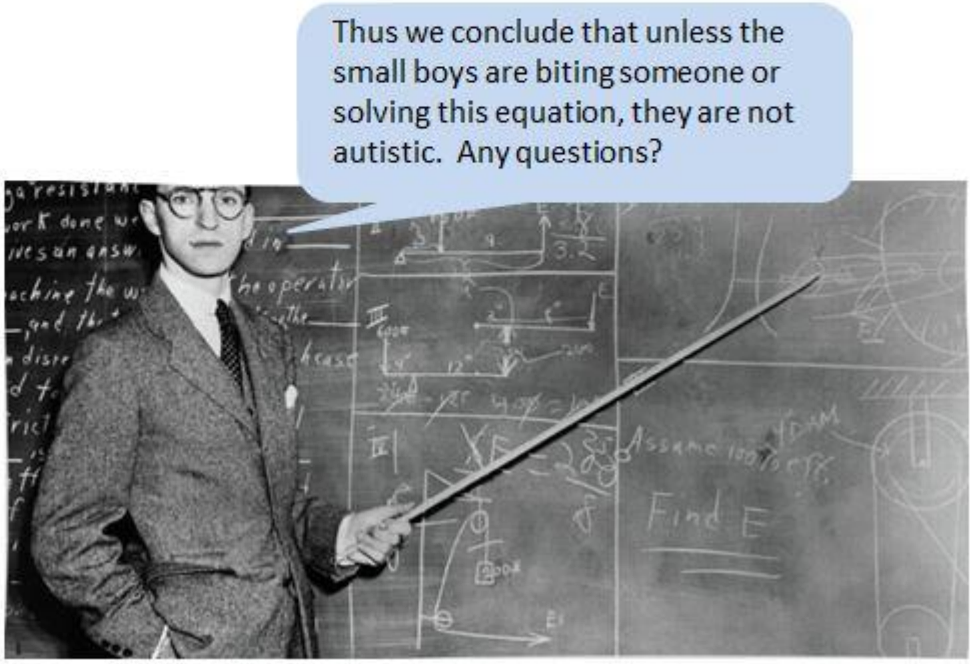


Figure 7: Autism: Is your training from the 1940s? (Memmott, 2019)

The researcher took the above picture from Ann Memmott's blog, "Autism. Is your training from the 1940s?" (Memmott, 2019). Here she states that some of today's manuals and training materials have only in part been upgraded, but still with wrong information. Memmott works in the Care, Education and Treatment Review programme and provides autistic advisory support (Memmott, 2021). Silberman, in his book, *Neurotribes* (2016), states that young adults have a different conversation. Theirs is more about how society refuses to accommodate cognitive disabilities in the same way as they do for physical disabilities (Silberman, 2016).

In the article 'Making the Future Together: Shaping Autism Research Through Meaningful Participation'. Autism research and its methods were looked at as there is often inferior application, and some evidence of communal disappointment. This was undertaken by a number of seminars, Shaping Autism Research, to include autistics and non-autistics (Fletcher-Watson, et al., 2019). This research was undertaken to ascertain if cooperation was possible in both directions between autistics and non-autistics.

The University of Cambridge have had to suspend their £3 million research study, called the Spectrum 10k project, as autistic campaigners, called Boycott Spectrum 10k, fear that they are looking for a 'cure' for autism. The University had been looking for 10000 autistic people to give a DNA sample from across the UK. The researchers say they want to examine how the environmental and biological factors impact on the well-being of autistic people and say they are not looking for a cure or to eradicate autism. The campaigners say that Prof Sir Simon Baron-Cohen has been closely associated with debunked theories. Another lead researcher, Daniel Geschwind, is a professor of human genetics, neurology, and psychiatry, looking to discover treatments for autism and is associated with organisations such as Cure Autism Now and Autism Speaks (Pring, 2021).

The ASA sent out an enforcement notice on 31st May 2018, though this was not made public until 22nd March 2019. The Enforcement Notice relates to CEASE therapy, and fake declarations by therapists about being able to treat or even 'cure' autism (CAP Compliance team, 2018).

As more and more autistic adults seek contact with other autistic adults they are turning to social media. Here are a couple of examples.

Autistic Empire, an autistic social organisation built by and for autistic adults to form community based on autism as a civic identity and to provide practical tools and services for all autistic people (Autistic Empire, 2017).

The researcher has expanded their research on “Surprise! You’re Autistic!” As an example of 21st Century, social media groups created for autistic people.

"Surprise! You’re Autistic!" is an official community of https://www.autastic.com for autistic adults over the age of twenty-eight and was created in 2018. It is run by autistic people, whose “collective mission is to educate, inspire, and empower each other to live our best lives after adult identification. Why? Because learning you're actually autistic late in life proves how badass you've been this entire time” (Autastic.com, 2020).

This Facebook group, like many others, have their own set of rules, in this case there are seven; centre late-identified #AutisticLife, bullying revokes membership, hate speech revokes membership, controversial hot topics will be removed, breaching privacy revokes membership, self-promotion is OK!'; Spaminess is absolutely not, Be Yourself! (Autastic.com, 2020).

"Surprise! You're Autistic!" also has free downloadable files for their members. These files are not only helpful but cover a wide spectrum of information. For example; a template to help with budgeting, a clinical account of Asperger syndrome, the process for adult diagnosis, OCD (Autastic.com, 2020).

The researcher has themselves been a member of this group for over a year. They have found it extremely helpful being able to connect with other autistic, mature, people. Having always known that they are “different” enlightened them that there are many others who experience the world in the same way as they do.

There are many autistic groups on platforms like Facebook, LinkedIn, Twitter, and Reddit among others.

Table 5: Social Media and Autism Forum Examples

Facebook	**Twitter**	**LinkedIn**	**Reddit**
Unashamed Voices of Autism	Neurodivergent Rebel	Autistic Executives and Managers	r/autism
Spectrum Woman	National Autistic Society	Neurodiversity Association	r/aspergirls
More Than One Neurotype	Weatherimgthespirets		r/autismTranslated
Surprise! You're Autistic	Erin Ekins (she/her)		r/neurodiversity
See Autistic Woman			r/autismUK

Along with online forums there has been a marked increase in books, television shows, documentaries and films explicitly depicting autistics during the 21st Century. These include; *Odd Girl Out: An Autistic Woman in a Neurotypical World*, *The Good Doctor; Atypical; The 'A' Word; Love on the Spectrum; Richard and Jaco: Life with Autism; Are you Autistic: Chris Packham on living with Asperger's.*

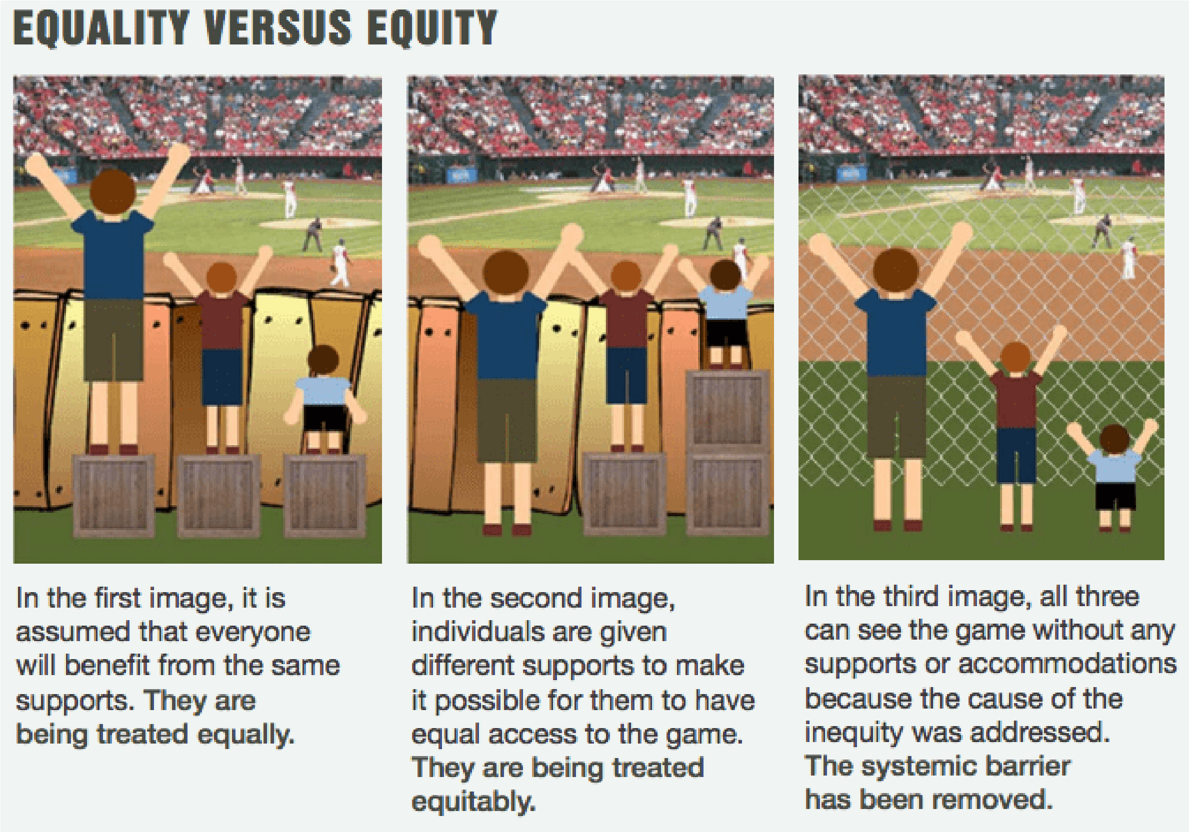
There are many different views on how 'disabilities' should be displayed in books, films and television. On the whole disabled and neurodiverse people accept that these stories and images are meant with a good heart, but the majority feel embarrassed and demoralised (Pulrang, 2019). The term now becoming more popular amongst the community of 'disabled' people is 'Inspiration Porn'. It is being likened to pornography, providing a superficial pleasure and gratification to the viewer, and yet causing harm to those being portrayed (Pulrang, 2019).

In Jan Grue's article she writes, "I propose the following definition: Inspiration Porn is the representation of disability as a desirable but undesired characteristic, usually by showing impairment as a visually or symbolically distinct biophysical deficit in one person, a deficit that can and must be overcome through the display of physical prowess" (Grue, 2016).

Samuel J Levine's book, *Was Yosef on the Spectrum? Understanding Joseph Through Torah, Midrash, and Classical Jewish Sources*, asks the question 'was Yosef (Joseph) autistic? This study analyses the life of Yosef as told in Genesis chapter 37 of the Bible (Levine, 2019).

6.7 Equity

The researcher themselves acknowledges that equality is a step in the right direction though their own personal desire is that society as a whole was more constructed around equity there would be a lesser divide if not total non-division between autistics and non-autistics and other marginalised communities. While the concept of equity can be traced back to Aristotle and his contemporaries (Beever, 2004), the modern understanding of this concept has only emerged within the social consciousness towards the end of the 20th Century.



EQUALITY VERSUS EQUITY

In the first image, it is assumed that everyone will benefit from the same supports. They are being treated equally.

In the second image, individuals are given different supports to make it possible for them to have equal access to the game. They are being treated equitably.

In the third image, all three can see the game without any supports or accommodations because the cause of the inequity was addressed. The systemic barrier has been removed.

Figure 8: Equality vs Equity (City for All Women Initiative, 2015)

Within the generalised population of the United Kingdom the conversation remains focused on equality rather than equity. Within the 21st Century this is an old concept just being rediscovered from the classical period. Within society equality and equity have different understandings. Equality usually equates to equal opportunities and support. Equity though goes that bit further by giving different levels of support depending on the need of the individual (Diffen, 2020). The researcher would advocate the third image in the above example of equality versus equity. Though if for whatever reason this was impossible, they feel that though not perfect the second image would be a vast improvement on equality. The researcher therefore also wonders if these changes have also taken effect in the area of education. Has the way autistics have been treated by teachers, lecturers and their cohort changed from the 20th Century to the 21st Century? (CoomberSewell Enterprises, 2020). The researcher ponders if this would make another area for research.

The researcher concludes that the social construction of autism is a never-ending phenomenon. This is being bought about by more and more autistics being Out and Proud but also by the general population acknowledging, if not the equity but at least the equality rights of the autistic person. This quote is taken from the Rt Hon Sajid Javid MP Secretary of State for Health and Social Care;

> *I encourage us all to take part in levelling up society. In particular, I hope that employers across the country, including the public sector, will help more autistic people get into work and make sure they provide the reasonable adjustments people need to thrive, making use of the support that is being made available.*

(Javid, 2021).

6.8 Conclusion

Though only into the first twenty-one years of the 21st Century the researcher can see that changes in all areas are escalating in both speed and impact. Many of the 19th Century dictionary definitions no longer exist or would be deemed politically incorrect. The medical diagnosis criteria has radically changed, with people across all genders, ages and all IQ levels qualifying for medical diagnosis. The Parliamentary Acts are far fewer with the majority being included in the Mental Health Act 1983. This act is currently under review with the intention of removing autism from it. This will provide autistic people with more protection from being sectioned and put into isolation. The researcher hypothesises that as the move for change continues that eventually, though probably not in their lifetime, equity will be achieved across all areas of society.

Discussion and Findings

7.1 Introduction

In this chapter the researcher will be discussing their findings from the literature contained in the 19th 20th and 21st Chapters and Tracking The Timeline Of Perceptions Of Autism In The United Kingdom From The 19th Century To The Current Day by answering the questions set out in their research questions:

> Has the development of autism diagnosis changed the social construct of autism or have autistics changed it for themselves? and what impact, if any, has that made on any disparity between the two groups?

The researcher concludes that just as in the case of what came first the chicken or the egg it is also hard to tell what came first, the more modern autistic diagnosis or autistics themselves who have changed the societal construction of autism, and therefore, perhaps, had an impact on how diagnosis is undertaken. Though there is still a disparity between autistics and non-autistics the researcher believes the gap is closing, as can be seen in the increasing impact of autistic self-advocacy. However, there are still some people looking to 'cure' autistics, and there are still autistics trying to hide the fact that they are autistic. There is still an equity gap between autistics and non-autistics, within the United Kingdom these gaps are starting to close.

With respect to the sub-questions:

a) Has the medical diagnosis of autism developed or changed from the 19th Century to the present day?

The researcher has compared the criteria of medical diagnosis from the 19th (Section 4.4) and 20th Centuries (5.4) and the beginning of the 21st Century (6.4) and has concluded that there have been significant changes throughout these three centuries. In the 19th Century the emphasis was mainly on people with lower IQ levels (4.4.1) and the aspects of disability that were physically manifested (Waltz & Shattock, 2004). As the medical research and the advancement of psychology developed across the 20th Century this established the new criteria for autism diagnosis (5.4.1). While controversial, the work of Asperger, among others, did much to significantly increase the subtleties involved in diagnosing autism and its associated conditions (Czech, 2018). This continued to develop over the 21st Century, creating a much more rounded diagnosis of autism, not only taking into consideration IQ levels, physical disabilities but also the complete functionality of that individual human as represented in DSM-V (First, et al., 2004).

b) Has the way society constructed their view of autism developed or changed from the 19th Century to the present day?

In the 19th Century autistic people were very much viewed as idiots or imbeciles (5.2) and there was little societal understanding of autistic people with higher IQs. It was not until the 20th Century, when the word autism was created, and then later by the attention of the media, that autism became better known within society, creating the change in society's views (5.5). As time evolved into the 21st Century, in addition to children and people with lower IQs being diagnosed there is a much broader range of humans being assessed. With the continued development of the media and the World Wide Web, both autistics and non-autistics are speaking out more about the differences and commonalities (6.5) between them and there is now a movement starting for the levelling up and equalising of these two conditions.

c) If the medical diagnosis and the societal construction of autism has changed from the 19th Century to the present day, has one influenced the other.

The researcher believes that both the medical diagnosis and the social construction of autism have equally influenced each other. This can be seen in many aspects of the research carried out including dictionary definitions, Acts of Parliament, and the creation of the World Wide Web. The researcher acknowledges that equity has not yet been reached but rather than the first few steps towards autistics and non-autistics being viewed with the same respect is now starting to happen (6.7). For this to grow, the researcher believes that autistic people, themselves included as an activist researcher, should follow in the footsteps of the gay rights movement, and take on the persona of being Out and Proud.

All the evidence for the researcher's answers to their questions can be found in the summary of the Discussion and Findings below.

The researcher acknowledges that social media can be used in a positive and in a negative way. There are numerous incidences of false information being posted and of course one person's opinion does not make it a truth. As stated in the 20th Century chapter (5.4.1), Andrew Wakefield published that the measles, mumps, and rubella vaccine caused autism. After this theory had been investigated and proved to be false it was withdrawn (Ambitious About Autism, 2021). The Lancet later rescinded the paper from their publication (The Health Foundation, 2010). Though a few social media sites did publish this rescinded information on the whole it was left unsaid. This is having a knock-on effect even in the 21st Century as many new mothers are still refusing to have their children inoculated with the MMR vaccination because of their fear that it causes autism. Mo Jang et al. (2017) cites Wilson and Keelan (2013) that scholars and health professionals are warning that the Internet, especially social media (6.5), may be boosting misleading medical and science information (Mo Jang et al., 2017). The researcher also acknowledges that towards the end of the 20th Century and continuing into the 21st Century, there has been a levelling up of disparities between lots of different human subsets, for example the gay community, people of ethnic minorities and of course the autistic communities.

In this chapter the researcher will use the same sequence as within all the three different century chapters. To the researcher this is a logical process promoting consistency. Therefore, the order for the Discussion and Findings will be set out in the following way: dictionary definitions, Acts of Parliament in the United Kingdom, main signs of autism, IQ classification, medical diagnosis, social constructionism, autistic “cures”.

7.2 Dictionary Definitions

The researcher has started this process by amalgamating the dictionary definitions (4.2, 5.2 and 6.2) from all the three centuries into one table below.

Table 4: Dictionary Definitions, 19th to 21st Century

Word or Phrase	**19th Century Dictionary Definitions**	**20th Century Dictionary Definitions**	**21st Century Dictionary Definitions**
Learning disabilities	Learning: "study, action of acquiring knowledge," Dis: word-forming element of Latin origin meaning "lack of". Ability: "state or condition of being able; capacity to do or act,"	Learning: knowledge got by study, esp. of language or literary or historical science. Disability: Thing, want, that prevents one's doing something.	A mental problem that people may have from birth, or that may be caused by illness or injury, that affects their ability to learn things.
Mental handicapped	Mental: Combinations such as mental patient (1859); mental hospital (1891). Mental health is attested by 1803; mental illness by 1819. Handicap: Meaning "put at a disadvantage" is from 1864	Mental: Of the mind; done by the mind. Handicap: (person) at disadvantage	This term was not within the dictionary so changed to 'Mentally handicapped': (of a person) slow to learn or to understand things because of a problem with the brain (old-fashioned, offensive)
Idiot	Uneducated or ignorant person. Idiot savant attested by 1870	Person so deficient in mind as to be permanently incapable of rational conduct.	A very stupid person

Imbecile	The sense shifted to "mentally weak or incapable" from mid-18c. (compare frail, which in provincial English also could mean "mentally weak"). As a noun, "feeble-minded person," it is attested from 1802. Traditionally an adult with a mental age of roughly 6 to 9 (above an idiot but beneath a moron).	Mentally weak, stupid, idiotic; physically weak; (n.) person of weak intellect	Having a very low level of intelligence (old-fashioned, offensive)
Feebleminded	Feeble: "lacking strength or vigor" Minded: "having a mind"	Feeble: Weak, infirm; deficient in character or intelligence; wanting in energy, force, or effect; dim, indistinct. Minded: Disposed (to do); having (specified) mind, as high, small	Having less than usual intelligence (old-fashioned, offensive)
Solitaries	Solitaire: "solitary person, recluse,"	Solitary: Living alone, not gregarious, without companions, unfrequented,	A person who chooses to live alone

		secluded, single, lonely, sole, kinds not living in communities; confinement, isolation in separate cell	
Moron	"one of the highest class of feeble-minded persons,"	"adult with a mental age between 8 and 12;" used as an insult since 1922 and subsequently dropped from technical use (Harper, 2020).	An offensive way of referring to somebody that you think is very stupid
Ament	"person born an idiot," 1894, from Latin amentia "madness,"	This word is not in The Concise Oxford Dictionary of Current English	This word is not in the Oxford Dictionary
Fatuity	"foolish, insipid"	Vacantly silly, purposeless, idiotic.	This term was not within the dictionary so changed to ‘Fatuous’: stupid
Cretin	"a dwarfed and deformed idiot"	Deformed idiot of a kind found esp. in Alpine valleys.	A very stupid person (informal, offensive)

In the dictionary definition section of the researcher's thesis, they noted that many of the terms originating in the 19th Century are now viewed as offensive and cruel in the 21st Century, such as imbecile, feebleminded, moron, and cretin. Back in the 19th and the early parts of the 20th Century these were commonly used words with no malice attached, often used by medical professionals, and were recognised as non-offensive terms. Dictionaries have evolved considerably since the first printed issue in 1755. Dictionaries develop and change according to how society uses language (Idea, 2021) and the use of these words reflect the push-pull relationship of influence between diagnostic language and society's embracing of it. For example, the word mental handicap is not in the 21st Century dictionary but the researcher noticed this had been changed to mentally handicapped and has a slightly different definition. In the 19th Century it was defined as "put at a disadvantage" whereas in the 21st Century it was defined as “slow to learn or to understand things because of a problem with the brain”. The 21st Century definitions are more precise and clearer than that of the 19th Century definition. The word fatuity no longer appears in the 21st Century dictionary, but the dictionary has a similar word, fatuous, with a very similar meaning. Ament, "person born an idiot" is no longer included in the 20th Century Concise Oxford Dictionary of Current English nor in 21st Century Oxford Advanced Learner's Dictionary. Though the word “idiot” is still in both of those dictionaries; 20th Century “Person so deficient in mind as to be permanently incapable of rational conduct” or in the 21st Century “A very stupid person”.

Dictionary definitions, on the whole throughout the three centuries, have become shorter and more concise, as demonstrated in Table 16 above. The researcher themselves has not heard any of these words used in the context of autism, either by autistics themselves or non-autistics, with the exception of learning disabilities, “a mental problem that people may have from birth, or that may be caused by illness or injury, that affects their ability to learn things" (Oxford Advanced Learner's Dictionary, 2020). This may only be because of their own advancing years and the social and professional circles they move in. This may not be the case throughout the whole population of the United Kingdom.

Furthermore, the societal and medical linguistics of the 21st Century, as a whole, have changed faster in comparison to previous centuries. This is demonstrated with the word Solitaries in the 19th Century which in the 20th and 21st Century would become known as Solitary, though keeping the same definition of living alone (6.5.1). Though the famous naturalist and autistic Chris Packham makes many documentaries and is often seen on the television and social media, he actually prefers to live a solitary existence with his beloved dog, Scratch. Packham states that he has no need for social contact (Skudra, 2021). This is quite common among autistics though like all humans they have their own individual reasons; the situation has become stressful, they find non-autistics hard to relate to, lack of confidence, not understanding socially acceptable behaviour, lack of support, and more (National Autistic Society, 2021a). The researcher themselves, though seen as quite a social person, internally would prefer isolation. One of their favourite daydreams is to escape to a desert island where there may be one or two cats for company but definitely no humans.

When the researcher considered their sub-questions, they saw clearly that the dictionary definitions have in fact significantly developed over the three centuries. An example of this would be in the term Mental Handicapped, used in the 19th Century, now known as Mentally Handicapped. Though this term, in the 21st Century, is being replaced in all official context by the term learning difficulties (Lexico, 2021). This has noticeably had a profound change in the way that society continues to construct their view of autism. Society has always constructed the ways that disabilities are viewed and how people are treated (Brauner, 2018). In the 21st Century society has become more aware of speaking in a “politically correct” way over many issues, so as not to cause offence, or in extreme cases breaking the laws of the United Kingdom concerning slander (Health and Safety Executive, 2021). Though it should be also noted that autistics themselves are reclaiming “non-politically correct” terms. Examples of this would be the reclaiming of the words autie, aspie and speckled (as in ‘speckle needs’, which are used within the autistic family of the researcher). This reclamation of terms within a family with an autistic member can be helpful (Attfield & Morgan, 2007) for confidence and communication.

Having considered the implications of the findings connected to dictionary definitions, attention will now turn to the influence of developing legislation.

7.3 Acts of Parliament

The researcher is aware that this is only a brief overview of the Acts of Parliament but is demonstrating how they have evolved over the last three centuries (4.3, 5.3 and 6.3).

Table 5: The Succession of Legislation from the 19th to the 21st Century

19th Century Acts of Parliament	**Repealed/ Superseded**	**20th Century Acts of Parliament**	**Repealed/ superseded**	**21st Century Acts of Parliament**
Criminal Lunatics Act 1800	→ [1]	Mental Health Act 1983	→	Mental Health Act 2007
County Asylums Act 1808		Mental Deficiency and Lunacy (Scotland) Act 1913	Mental Health Act 1959	
Marriage of Lunatics Act 1811	→			Assisted Decision-Making (Capacity) Act 2015
Madhouse (Scotland) Act 1815				
Criminal Lunatics Amendment Act 1815		Mental Treatment Act 1930	Mental Health Act 1959	
Irish Lunatic Asylums for the Poor Act 1817				
Pauper Lunatics Act 1819	County Asylums Act 1828			
Lunacy (Ireland) Act 1821				Mental Capacity Act 2005
County Asylums Act 1828				
Madhouse Act 1828	Madhouse Act 1832			
Chancery Lunatics Property Act 1828	Lunacy Regulation Bill 1853			

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[1] The use of arrows in this table denote occasions were legislation has been directly superseded by the next mentioned piece of legislation. Where there are no arrows, this denotes a more indirect effect, linkage or causation.

Madhouse Act 1832	County Asylums Act 1845 and Lunacy Act 1845			
County Asylums Act 1845 and Lunacy Act 1845	Lunacy Act of 1890			
Lunacy (Scotland) Act 1857				
Idiots Act 1886	→	Mental Deficiency Act 1913	Mental Health Act 1959	
Lunacy (vacating of Seats) Act 1886	→	Mental Health Act 1959	→	Mental health (Discrimination) Act 2013
Lunacy Act of 1890	→	Mental Health Act 1959	→	Mental health (Discrimination) Act 2013

Many of the earlier Parliamentary Acts throughout the 19th Century may have come about through good intentions but the researcher speculates that they may have been open to abuse and manipulation because of the development of psychiatry and psychology, which were very new sciences at the time; this may well have made the Acts blunt instruments.

Before and during the 18th Century, Parliament was made up of wealthy landowners who prioritised themselves over other less fortunate people, including those with what we would now diagnose as autistic, in the realms of prosperity and power. During the 19th Century there was a surge in the growth of industry causing the shrinkage of agriculture over the United Kingdom as a whole. This led to the working and middle classes demand for equality and fairness though it took a considerable time for Parliament to be more representative (UK Parliament, 2020). The researcher would question whether this has been fulfilled as a whole and would refer the reader to the section in the 21st Century looking at equity.

Many of the vast number of 19th Century Acts of Parliament relating to how we treat and manage autism had been repealed or suspended by the 21st Century. The Mental Health Act 1983, which was updated in April 2015, now has prevalence over many forms of disability legislation including those addressing autism. Within the Code it is recognised that autism is not like other serious mental illnesses unless there is displayed aggressive or seriously irresponsible behaviour (Butler-Cole, 2015). The Code goes on to state, “Hospitals are not homes, and most support for people with autism should be provided in a local community setting” (Department of Health, 2015). It also lays out very clearly that if an autistic person needs to be detained it should be for as short a period as possible (Butler-Cole, 2015). A memorandum submitted by the National Autistic Society to Parliament in 2007, section 11 and 12, reads as follows:

> *11. Therefore, if a person with an ASD was detained under the Mental Health Act 1983 and did not have a mental illness, it would be expected that they will have demonstrated 'abnormally aggressive or seriously irresponsible' conduct.*
>
> *12. However, there is an added complication from case law: 'mental illness' is assessed on the basis of behaviour from the layperson's point of view. So, some people with an ASD may be detained under the mental illness category, even without a mental illness. There is no clear national guideline on this; it is not supported by the Royal College of Psychiatrists or the broader community [2]; and the National Autistic Society believes it is bad practice.* (www.parliament.uk, 2007).

This is a clear indication of how legislation and society interacts and influence each other. The researcher suggests that before the proposed changes to the Mental Health Act come into force there should be a clear undertaking for them to be scrutinised and updated by people medically diagnosed with ASC.

There have been many and various newspaper articles citing the lack of knowledge by the medical fraternity on how autistic people behave differently to non-autistics. Along with the major impact this has on autistic people when they are incarcerated, and their needs not taken into consideration. The researcher highlights an article in the Independent newspaper that reports on a 31-year-old man who was detained in a secure mental health unit for 14 years even though there had been multiple warnings that this detention was exacerbating his autism (Lintern, 2015). The Independent, in the same report, highlights the latest data of the time from the NHS. The number of autistics being detained in March 2015 rose from 295 to 610 by the June of the same year (Lintern, 2015). In 2021 Jayne McCubbin and Ruth Clegg, of BBC News undertook an investigation into how many people with learning disabilities and autism, in England, were being held in secure Assessment and Treatment Units (ATU) for 20 years or more. They discovered the number to be in excess of one hundred people (McCubbin & Clegg, 2021).

Another example of this is a 17-year-old autistic woman, Bethany, who also suffered from high levels of anxiety. For the previous two years of her life, she had been locked in a seclusion room in a private hospital in Northamptonshire. In 2016 she was sectioned and detained under the Mental Health Act (MHA). Bethany spent 21 months in solitary confinement, and inactivity, which led to clinical obesity. When her father, Jeremy, tried to go public to expose what was happening to his daughter, Walsall Council served him with an injunction order so as not to allow him to share details of his daughter's plight (Hurst, 2018). This was later withdrawn (Autism Injustice, 2021). A lot of her problems were caused by sensory overload. This can be noise, harsh lighting, rapid movements, confined spaces and so forth, potentially leading to panic attacks and meltdowns. Instead of working with her and placing her in appropriate accommodation where these sensory issues would not have been a problem, she was placed in solitary confinement, in a noisy environment, with harsh lighting, in a confined space, which led to her anxiety being so overpowering that it caused her to become aggressive. It was not until December 2019 that her father won his case to have her placed in a more appropriate setting. She is now in supported living and has a team of dedicated staff to support her who understand her need for fresh air, music, and animals. Her life has totally transformed (Autism Injustice, 2021).

Throughout the 19th Century literature review chapter, it became apparent to the researcher that the only people who came to the attention of the medical profession were those with severe learning difficulties and or extreme behavioural tendencies (4.4). In the case of the lower classes these people would have probably been institutionalised in mental institution or workhouses whereas in the higher classes they would have been hidden away in isolated properties such as mansion houses, in the attic or cellar of the main residence, and in private madhouses. Examples of this can be found within fictional characters like Barnaby Rudge (see p. 68) and Jane Eyre (see p. 69). This social construct of autism as fascinating, appalling or amusing can be seen extended into the age of television with characters such as Sheldon in *The Big Bang Theory* and programmes like *Atypical* reflecting on a society which is both more accepting of and challenged by the realities of autism.

It is apparent within the sub-questions that as the Parliamentary Acts developed and become more concise across the three centuries that this had an impact on the way that society treated autistics. There is still a strong movement to have autism removed from the Mental Health Act.

Though the researcher acknowledges that the above table of Parliamentary Acts does not reflect every single piece of legislation passed, it does give a substantial overview to how these have evolved and developed over these last three centuries. The researcher acknowledges that they could have also looked at other Acts of Parliament such as the 1689 English Bill of Rights, the 1948 Universal Declaration of Human Rights Act, and the 1995 Disability Discrimination Act (Equality and Human Rights Commission, 2018). Though this may have given the researcher a different interpretation they decided to focus on how legislation interacts with the medicalisation of autism.

At the current time the 20th Century Mental Health Act is being reviewed through consultation with the autistic and wider community, with the potential of having autism removed from the Mental Health Act. The channels that autistics use for information tends to guide them to the Mental Health Act rather than more generalised equalities legislation (National Autistic Society, 2021). The researcher believes that there is an entwinement between the medical diagnosis of autism, the Acts of Parliament concerning mental health and how society constructs its opinion of autism. See conclusion (Figure 9) for a visual representation of this relationship.

7.4 Medical Diagnosis

Table 6: IQ classifications from the 19th to the 21st Centuries

20th Century Classification of Intellectual Impairment	**20th Century IQ Range**	**21st IQ Classification**	**21st Century IQ Range ("deviation IQ")**
		80–89	Low average
		70–79	Borderline impaired or delayed
Mild Mental Retardation	50-70	55–69	Mildly impaired or delayed
Moderate mental retardation	35-49	40–54	Moderately impaired or delayed
Severe mental retardation	20-34		
Profound mental retardation	Under 20		

The first documented study of human intelligence was started in the late 1800s by Francis Galton (1822-1911). He commenced by trying to measure the physical characteristics, reaction times, and other physical and sensory qualities. Galton is regarded as one of the forefathers of today’s intelligence research and he pioneered psychometric and statistical methods. Galton’s work in testing hypotheses was the springboard for later work by researchers (Stough, 2015).

In the 19th Century it was commonly thought that autistic people had low IQs (section 4.4.1). Leo Kanner, however, wondered if the lack of social and communication skills was in fact masking their true intelligence (AppliedBehaviourAnalysisEdu.org, 2021). By the 20th Century studies showed that about a fifth of the people with autism fell within the normal IQ range (5.4.1). This increased again in the 21st Century (6.4.1) when a US study found that over half of autistic children had an average or above average IQ (Sarris, 2021).

On looking at the cross over of data on the above table the researcher notes that there have been some small difference in the IQ results, mainly in the area of the linguistics, over the last hundred years thus having little impact on the development of autism diagnostics.

Table 7: Changes in IQ categorisation and language

Mild Mental Retardation	50-70	55–69	Mildly impaired or delayed
Moderate mental retardation	35-49	40–54	Moderately impaired or delayed

It has become very apparent to the researcher that the IQ test has little impact on the medical diagnosis of autism. IQ results normally indicate a person’s ability to communicate and adapt to the everchanging daily life. However, the IQ test does not give good cognitive indicators or of global functioning Rudacille (2011). From the point of view that there are many different versions of autism that are not related to the individuals IQ levels. For example, society may judge someone with physical disabilities, unnatural facial expressions, selective mutism, and other manifestations as having a very low IQ when in fact that person may well have a PhD. Charman et al (2011) is cited within the NICE Guidelines, stating that 50% of autistics have a lower IQ than 70, but there is a gap between their intellectual and adaptive skills, the latter having the biggest impact on their everyday lives (National Collaborating Centre For Mental Health , n.d.).

7.4.1 Main signs of Autism, children, and adults

Table 8: Main signs of autism defined from the 19th to the 21st Centuries[2]

19th Century	**20th Century**	**21st Century**
Severe feeding and gastrointestinal problems	Pedantic or repeated speech	Not understanding others' thoughts and feelings
Developmental delay	Non-verbal communication	Anxiety in social situations
Not toilet trained	Lack of social interaction and ability to use rules and understand social behaviours	Hard to make friends/prefer to be alone
Oral-motor problems and non-verbal	Repetitive activities and resistance to change	Coming over as blunt, rude or not interested in others
Nocturnal seizures	Lack of motor co-ordination	Hard to express own feelings
Repetitive movements	Unusual abilities in skills and interest	Taking things very literally
	Negative experiences at school	Disliking change to daily routines

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[2] This table draws together tables from the three literature chapters (4.4.2, 5.4, 6.4) and therefore draws on a variety of sources which are referenced within those chapters

In the table above the researcher notes that the diagnostic development of autism has vastly changed throughout the three centuries and will continue to change as time unfolds. DSM was first introduced in 1952, it only contained one hundred and thirty pages with one hundred and six diagnostic descriptions. However, DSM-V, published in 2013, contains nine hundred and forty-seven pages and with approximately three hundred disorders. Prior to 1980, autism only appeared in DSM to describe schizophrenia. DSM-lll included infantile autism, though the revised edition DSM-lll-R changed the wording to autistic disorder (Sarrett, 2019). The introduction of DSM-V has had the biggest impact on the diagnostic criteria of autism, though this has raised a few concerns around the area of the impact going forward (King, et al., 2016). However, a group of twelve researchers have suggested that DSM-V fails to weigh in the social factors, for example, stereotypes, community awareness, and autism. The researcher recommends that DSM-V is systematically reviewed to ensure the accuracy of psychiatric diagnoses (LeBano, 2013).

In the 19th and 20th Centuries the researcher noted that there was an emphasis on non-verbal communication, though by the 21st Century it had shifted to pedantic and repeated speech coming over as blunt, rude or being uninterested in others. All of these traits can also be found in non-autistics. Predominantly in the 19th Century there was much concern over physical problems, whether internally or externally, though by the 20th Century the emphasis has changed to purely external problems, as in repetitive movements and lack of motor coordination. By the 21st Century there is no mention of either of these phenomena, focusing entirely on emotional and social impairments. By this the researcher is referring to some autistic people not liking to mix with other people, or maybe having stims such as hand flapping, hair pulling and so forth. This would then impact on how autism is diagnosed by healthcare and autism service providers if their knowledge of how autistic people communicate and interact with others is incomplete (Papadopoulos, 2016).

All human beings mask, “The process by which a stimulus (usually visual or auditory) is obscured by the presence of another almost simultaneous stimulus” (Collins Dictionary, 2021). An example of this might be when not seeing why a certain joke may be funny, the person would laugh anyway. They would do this to hide that they do not understand the joke in case they are viewed as not being very intelligent. Though it is said that women on the whole are better the men at masking. There is evidence to show that autistic have got masking down to a fine art, though autistic women are still perceived as being better maskers than autistic men. No two humans mask in the same way. Masking is often learnt through childhood as a way of gaining approval or acceptance, though they may not be actively conscious of doing this. It is much harder to maintain masking when the individual is unwell, feeling stressed or anxious (Asad, 2021). Autistics use masking extensively to conform to the non-autistics’ social construct of manners, body language and other societal rules.

There are some doctors in Great Britain, who during the 21st Century Covid-19 outbreak, have called for a blanket ‘do not resuscitate’ order for all autistic adults who contract the disease, without their or their family’s consent (Nuwer, 2020). This reflects the societal construct within which the medical profession sits, suggesting that even within the 21st Century autistics and people with other differences are considered less worthy of efforts to preserve life than those who fit the societal norms. The researcher’s own personal view is that anyone with any condition, unless they or their family give consent, should be resuscitated. As an older autistic themselves the researcher finds this discloser extremely offensive and somewhat scary.

The stark realities of the impact of this attitude is laid out below. This source has deliberately not been paraphrased as to do so would risk minimising the realities it contains.

> *In this article, learning disability is based on a clinical diagnosis by a medical practitioner, whereas disability was defined based on responses to a question on the 2011 Census, which will vary according to individuals' own interpretations and experiences* (Office of National Statisticss, 2021).

> *Between 24 January and 20 November 2020 in England, the risk of death involving the coronavirus (COVID-19) was 3.1 times greater for more-disabled men and 1.9 times greater for less-disabled men, compared with non-disabled men; among women, the risk of death was 3.5 times greater for more-disabled women and 2.0 times greater for less-disabled women, compared with non-disabled women* (Office of National Statisticss, 2021).

> *Looking at people with a medically diagnosed learning disability, the risk of death involving COVID-19 was 3.7 times greater for both men and women compared with people who did not have a learning disability; after using statistical models to adjust for a range of factors, a raised risk of 1.7 times remained unexplained for both sexes* (Office of National Statistics, 2021).

In light of the above statistics the researcher asks the question, was the disparity in deaths between the disabled and those medically diagnosed with a learning disability caused by their condition or by the doctors' decision not to resuscitate? Does this indicate the medical position within a social construct whereby those with autism and other conditions are viewed as less than or other due to their costs to the NHS and or their limited contribution to a capitalist society. The researcher has noted that this would be worthy of further research in the future.

Richard Wood’s article (2017), “Exploring how the social model of disability can be reinvigorated for autism: in response to Jonathan Levitt” addresses the primary goal of the social model to remove the focus from the individual impairments and turn instead towards the societal structures. He continues to consider how institutions have a duty to take responsibility for undertaking these adjustments. He goes on to communicate the need to change the law or fully implement existing legislation, starting with local authorities and the NHS trusts obligation to the Autism Act 2009 and making reasonable adjustments under the Equality Act 2010. Wood also recommends changing to the positive nuances of autism by no longer using toxic words like ’disorder’ and ‘deficit’ (Woods, 2017).

In regard to the medical diagnosis itself this has developed and changed considerably over the centuries which has impacted on societies construction of what it means to be autistic. As the testing for IQ levels has become more common during diagnose it has highlighted that autistics can be placed anywhere on the intellectual spectrum. This changed the perception of autism both within the medical fraternity and society. The researcher acknowledges that for one to have any impact on the other both the medical and society must be willing to make the changes.

7.5 Social Construction

7.5.1 Autistic “Cures”

By this the researcher is using the term ‘cures’ to indicate society’s attempt to either remove autism completely from a person’s life or to train them to behave in a non-autistic way. There are no “treatments” or “cures” for autism in itself though there are medicines and diets that will help other conditions that may affect autistic people (NHS, 2019).

Back in the 19th Century the word autism had not yet been created but for those children, who in today's society would have been diagnosed with autism, there was no emphasis on curing them. The only medical intervention would have been to relive severe bowel complaints and respite from the poverty that they lived in. By the 20th Century there was a shift to identify either "cures" or to eradicate autistics from the world population by using eugenics. Some of the 20th Century "cures" would involve the mother tightly holding onto the child until they complied, this later evolved into ABA, which is still used today in the 21st Century (Autism Speaks, 2019). Increasingly, robot interaction is also being used with autistic children to have them conform to live in a non-autistic way (Shamsuddin, et al., 2012).

Warren (2011) concludes in 'A Systematic Review of Early Intensive Intervention for Autism Spectrum Disorders' (p. e1310) 'There is not yet adequate evidence to pinpoint specific behavioural intervention approaches that are the most effective for individual children with ASDs' (Warren, et al., 2011). The researcher has a young family member who was subjected to ABA in their SEN senior, school. This person was punished for non-compliance by being placed in isolation, in a windowless small room, until they would comply. This has had a long-term effect on their mental wellbeing, including developing anorexia, selective mutism, and reclusiveness. The journal article, History of the Human Sciences, cites a former ABA practitioner saying that autistic people themselves, who have been subjected to ABA, are left traumatised and devalued (Kirkham, 2017).

7.5.2 Social Media

The use of social media has greatly increased over the last thirty to forty years (6.5.1). Though used over all generations it is greatly perceived to be in the main used by the younger generations. Though the World Wide Web is a huge asset to mankind it can also have adverse effects especially in the areas of fake news, sexual exploitation, self-harm and increasing the spread of social anxiety (HelpGuide, 2020). Often people will look to social media platforms to find the answers that they are seeking rather than go to trained professionals.

By the end of the 20th Century and into the 21st Century there has been a significant move in how society viewed autism in the United Kingdom. “Cures” were being examined both by the families of autistic people and society as a whole. But in opposition to this view, autistics were turning to social media in an attempt to educate non-autistics that autistics are as valuable as they are (Corbett, 2014). They are also highlighting that to be autistic does not automatically mean that the autistic person has learning difficulties, though they may learn in a different way to non-autistics (Bailey, 2020).

Through the social media platform of LinkedIn, the researcher discovered a link to the website Valuable 500. This website is a collective of 500 CEOs and their influential global companies working together for disability inclusion and system changes (Valuable 500, 2021).

7.6 Researcher’s Reflection

The researcher has enjoyed this exploration into the history of autism, both from a medical and societal perspective. Over the course of writing this thesis they have learnt and unlearned aspects of autism that they either did not know or thought they knew but were incorrect. An example of this would be concerning Asperger and the misconception of his involvement and thinking in sending some children to the Nazi concentration camps.

The researchers own view at the beginning of this thesis was that autistics alone were making the change in the social construction of autism. Through their research they have discovered that in fact it is a mixture of the dictionary definitions, Acts of Parliament, medical diagnosis, and the social construction, both verbally and through social media, of autism by both autistics and non-autistics that has changed the view of autism in the United Kingdom.

There were a few challenges the researcher encountered during the research, specifically the development of the theoretical framework, and the changes to their methodology they had to make because of the Covid-19 related closure of the Archives. For an older and dyslexic researcher, the introduction of complicated, and new academic words was both challenging and time-consuming. The leap from undertaking their dissertation at the end of their Bachelor's degree to undertaking this thesis was much larger than they had anticipated. In hindsight the researcher feels that it would have been beneficial to have undertaken training specifically in this area.

The researcher particularly enjoyed their research covering the 19th, 20th, and 21st centuries. The researcher found new and intriguing information about autism which they had not been aware of before. One of these discoveries was about the complexity surrounding the reason that Asperger is no longer used as a diagnostic name.

The researcher is now seriously considering continuing their research into the many different aspects of autism both past and present by undertaking a PhD by publication

Conclusion

8.1 Introduction

In this chapter the researcher will be taking an overview of all the previous chapters. They will then amalgamate all the data collected into their conclusion including if their original questions were adequately answered. The researcher will look at their original opinion of the outcome of this research to see whether it has changed and developed over the course of this thesis.

In the introduction the researcher laid out the structure for the rest of this thesis. This included that this would be a literature review looking at both the medical diagnosis of autism and the social construction of autism from the 19th Century through to the present day. It was the researcher's intention to undertake research at various archival establishments. At the beginning of their research, they had undertaken a brief visit to two archives but because of Covid-19 they were unable to continue with this line of research. The researcher also considered their own positioning in the context of this research as they are medically diagnosed autistic with 66% of their immediate and wider family being on the autistic spectrum.

The theoretical framework chapter covered a literature review on; ontological/ontology, epistemology/epistemological, phenomenology, axiology as philosophical considerations. Methodological approaches of positivism, postpositivism, pragmatism, interpretivism and constructivism, transformativism, social construction, where explored before finally settling on the researcher position. This was followed by the definition process and the researcher's questions, these being;

Has the development of autism diagnosis changed the social construct of autism or have autistics changed it for themselves? and what impact, if any, has that made on any disparity between the two groups?

This was expressed as a number of sub-questions:

Has the medical diagnosis of autism developed/changed from the 19th Century to the present day?

Has the way society constructed their view of autism developed/changed from the 19th Century to the present day?

The next chapter outlined the methodology that the researcher would use. The researchers stated they would be using an online desk based, integrative literature review, along with archive research. The researcher was unable to follow-up on any archive research due to the current pandemic of Covid-19 and the government restrictions. The researcher then went on to discuss why they had chosen this method and demonstrated their selection process and criteria of resources.

The next three chapters of the thesis covered an extensive literature review and analysis of autism in the 19th Century, 20th Century and the first twenty-one years of the 21st Century bringing this up to the present day.

Each of these three chapters contain the dictionary definitions, initially used in the 19th Century to describe those who in the present day would probably have been diagnosed as autistic. The researcher then went on to look at the Acts of Parliament in The United Kingdom covering the above three centuries that could have been applied to people on the autistic spectrum. This was followed by the medical diagnosis of autism, recognising that the word autism was not used in the 19th Century and therefore looked at relevant diagnosis that would fit the autistic criteria. Next the researcher looked at the social construction of autism and autistic “cures” throughout the three centuries.

It should also be noted that the researcher examined the classification of intellectual impairments using IQ ranges only within the 20th and 21st Century as this had not yet been created in the 19th Century. The researcher went on to acknowledge the development of the World Wide Web at the end of the 20th Century. Within the 21st Century chapter the researcher looked at the social media platforms that autistic groups were using.

Finally, the researcher collated and analysed all the information collected into the Discussions and Findings chapter. The researcher compared the information they had collected in each chapter to ascertain if they had answered the sub-questions of **Tracking The Timeline Of Perceptions Of Autism In The United Kingdom From The 19th Century To The Current Day.** They also looked to ascertain if there had been any changes or development in the way autism is looked upon today in the 21st Century. The researcher laid out how their own opinion had changed from believing that autistic people had changed the way that society constructed autism to acknowledging that though this is true in part it is also because of the ongoing medical diagnosis, social media, and the change of attitude in human society in The United Kingdom as a whole. See Figure 9 below for a visual representation.

The researcher was then able to ask specific questions about what is driving the change in the social construction of autism. Is it the change to how the autistic diagnosis tools have developed or the way autistics themselves present themselves to the communities they associate with? Unsurprisingly there are still ‘cures’ for the elimination of autism, along with autistics themselves desperate to hide their autistic ways in an effort to fit into the non-autistic world. This all adds to the equity split between autistics and non-autistics but despite this, the direction of travel is generally going forward. Though the researcher acknowledges that there is incongruence between autistics and non-autistics they do believes the chasm is slowly starting to close. The encouraging influence of self-advocacy by the autistic community and their allies, along with the updating of medical diagnostics and dictionary definitions is resulting in a slow but sure change to the social construction.

The researcher questions if this might then be the case in other social discrimination cases, e.g., Lesbian, Gay, Bisexual, Transgender, Queer or Questioning +, Black Lives Matters, and others, and how society might go about rectifying this phenomenon, if indeed both communities desire this. This study may then be the basis of further research to be undertaken at a later date.

8.2 Areas for Further Research

There are a number of areas where the scope of this project has meant that the researcher has had to curtail their curiosity and activities. All of these warrant further research and would make valuable additions to the scholastic resource. This list is not exhaustive, neither is it proposed that this researcher would be responsible for all the work, although the concept of some collaborative work, even potentially across disciplines is attractive. These areas could include:

The researcher feels that the following area is of the utmost importance to society's view of the historico-social view of autism and would be their first undertaking for their PhD. A historic re-framing of Asperger in his role as scientist and his efforts to save some (those diagnosed as having Asperger's) at the cost of others (those with learning difficulties and autism). The researcher is mindful that Asperger's work is being lost because of the miss-information being circulated. This piece of work would be undertaken by an extensive literature review including research into the relevant archives. Once peer-reviewed the article would need to be circulated amongst the autistic and non-autistic communities via such platforms as the National Autistic Society and the NHS.

As an older autistic who was not diagnosed until in their 60s the researcher would like to promote this inequality and help it to become equal with other age groups. Autism diagnosis in older people is a new area being developed primarily in the 21st Century. The person doing this research would need to have access to older people who have either recently been medically diagnosed or those who suspect they may be autistic. Similar work is being undertaken by Nancy Clark with the older LGBTQ+ communities and how they are viewed by society and the health care system. This may be a good model for such research.

Though the researcher feels that self-diagnosis is a good first step they also believe that a full medical diagnosis is important. Autism and self-diagnosis is becoming more common due to the prevalence of the World Wide Web and therefore easier access to the criteria of autism, though there are some sites publishing misinformation. This research would be carried out with questionnaires, group forums and interviews as well as literature reviews.

The above three issues were touched upon in the cause of this thesis, but a full investigation was outside the scope of this research.

Below are some further areas that the researcher would be interested in, the ideas for which were sparked by conversations and the literature read in the cause of this work but had to be discarded as they did not fit the brief.

Though the researcher has no desire to pursue the following area they do still believe that it would be an important area to research: The role of autism in professional creatives, this would involve theatre, music, and the arts. This piece of research could be undertaken both historically and to the present age. This would involve both literature reviews, archive research and interviews of present-day artists.

The researcher finds this area of personal interest and would be very interested in the outcome of further research: The incidence of LGBTQIA+ and autism is becoming more commonly linked within the 21st Century. This research could be undertaken by interview, surveys, and historical research.

Through the research into the 19th Century the researcher's interest was awakened into this area of history: Autism in the Victorian age, though not named as autism, would need to be undertaken through extensive archival research, to include both the lower and higher classes.

This would be a new and unexplored area of autism for the researcher: Savantism is often associated with autistic people who have other socially diverse characteristics. This research would both be historical and undertaken by interview of people with Savantism.

8.3 Final reflections

Needless to say, the researcher has thoroughly enjoyed their exploration into the deeper world of academia, though this has bought some major challenges in the area of theoretical framework and methodology due to the Covid-19 pandemic.

The work of the researcher has ignited a hunger to continue with their research into the profound and intriguing life of the autistic. The researcher believes there are many more fascinating areas to be discovered as they continue on their journey of research.

At the beginning the researcher's view of the disparity between autistics and non-autistics was laid very much at the door of the non-autistics. Through their exploration there have been many discoveries of deeper knowledge of autism and the development of the dictionary, medical, legislation, and social construction of this amazing and diverse condition. It has been the combination of all four of these that has led to the slow but encouraging closing of the societal gap between autistics and non-autistics in the United Kingdom.

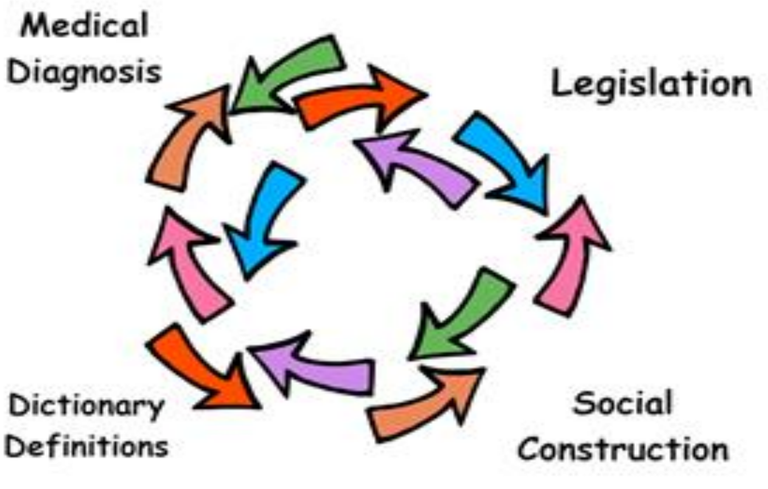

Figure 9: A non-hierarchical representation of the interactions of Legislation, Dictionary Definitions, Medical Diagnosis and Social Construction in the evolution of autism perspectives.

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Appendix 1

Dictionary Definitions 19th to 21st Centuries

Table 11: 19th Century Dictionary Definitions

Word or Phrase	Dictionary Definitions	Commentary
Learning disabilities	Learning: "study, action of acquiring knowledge," Dis: word-forming element of Latin origin meaning "lack of". Ability: "state or condition of being able; capacity to do or act"	This is an umbrella term to describe any neurological impairment, not just autism. George Edward Shuttleworth, in the 1870s, was a leading innovator in psychiatric services and legislation, predominantly in distinguishing those with learning disabilities from the insane (Langdon Down Museum of Learning Disability, 2020).
Mental handicapped	Mental: Combinations such as mental patient (1859); mental hospital (1891). Mental health is attested by 1803; mental illness by 1819. Handicap: Meaning "put at a disadvantage" is from 1864	In 1845 once a doctor had diagnosed a person with a mental illness, they could be moved from institution to institution against that person's will. This is still the case today under DHSS, 1987 (Barnes, 1991). The current battle to get this changed is discussed in the 21st century chapter.

Idiot	Uneducated or ignorant person. Idiot savant attested by 1870	The label of “idiot” signified a person who had not mentally expanded since birth with no true chance at improving their mental faculties (Langdon Down, 1990).
Imbecile	The sense shifted to "mentally weak or incapable" from the middle of the 18th Century (compare frail, which in provincial English also could mean "mentally weak"). As a noun, "feeble-minded person," it is attested from 1802. Traditionally an adult with a mental age of roughly 6 to 9 (above an idiot but beneath a moron).	In 1886 the Idiot’s Act was passed, it made the distinction between lunatics, idiots, and imbeciles (The Social Historian, 2018).
Feebleminded	Feeble: "lacking strength or vigor" Minded: "having a mind"	The feebleminded were seen as burdensome in the 19th century, though this changed in linguistics by the beginning of the 20th century to ‘menacing moron’. The feebleminded here categorised by their low intelligence and prolificacy from generation to generation (Trent, 2017).
Solitaries	Solitaire: "solitary person, recluse,"	Taken from the Sage journal website, ‘reviews etiological and comparative evidence supporting the hypothesis that some genes associated with the

		autism spectrum were naturally selected and represent the adaptive benefits of being cognitively suited for solitary foraging' (Reser, 2011). This complex statement suggests that autistics are genetically more suited to living alone, and potentially living off the land through gleaning and natural food collection.
Moron	"one of the highest class of feeble-minded persons,"	The following quote was taken directly from the book *Backward and Feeble-Minded Children*, published in 1912 and held in the library of Boston Psychopathic Hospital. "Those whose mental development is above that of an imbecile but does not exceed that of a normal child of about twelve years" (Burke Huey, 1912).
Ament	"person born an idiot," 1894, from Latin amentia "madness,"	In editorials published between 1905 and 1908, Bolton set out an up-to-the-minute psycho-pathological classificatory system, founded on a comprehensive empirical study of asylum patients and their brains. This system contained two overarching classifications: amentia and dementia (Andrews, 2014).
Fatuity	"foolish, insipid"	The Lunacy Regulation Bill specified that medical testaments kept to the extensive thoroughfare of "fact" and not drift into the hypothetical. An example of this drifting was given as "the learned gentleman who diagnosed "fatuity and mania" in a female defendant because she could not

		tell “how much £100 a year was a week,” an impromptu sum which also flummoxed its proposer” (Walsh, 1998).
Cretin	"a dwarfed and deformed idiot"	“Unable to walk, —usually deaf and dumb, — with bleared eyes, and head of disproportionate size, — brown, flabby, and leprous skin, — a huge goitre descending from the throat and resting upon the breast, — an abdomen enormously distended — the lower limbs crooked, weak, and ill-shaped, — without the power of utterance, or thoughts to utter, — and generally incapable of seeing, not from defect of the visual organs, but from want of capacity to fix the eye upon any object, — the cretin seems beyond the reach of human sympathy or aid. In intelligence he is far below the horse, the dog, the monkey, or even the swine; the only instincts of his nature are hunger and lust, and even these are fitful and irregular” (Brockett, 1858).

Table 12: 20th Century Dictionary Definitions

Word or Phrase	**Dictionary Definitions**	**Commentary**
Learning disabilities	Learning: knowledge got by study, especially of language, literary or historical science. Disability: Thing that prevents one doing something.	This terminology had been previously known as ‘mental handicap, mental deficiency, along with other terms (Jarrett, 2012).
Mental Handicapped	Mental: Of the mind; done by the mind. Handicap: (person) at disadvantage	Since the beginning of the 20th Century many people who were identified as mentally handicapped were moved from isolated institutions back into mainstream society (Bonnstetter, 1986).
Idiot	Person so deficient in mind as to be permanently incapable of rational conduct.	In the 20th Century psychologists, mental scientists, and social theorists, saw idiots in their institutions as valuable illuminating pretences and investigational tools for their hypotheses of animal and human mind. They positioned idiots close to, or even among, non-human animals in public perception (Jarrett, 2020). Therefore, they were viewed as little more than lab rats.
Imbecile	Mentally weak, stupid, idiotic; physically weak; person of weak intellect	The Mental Deficiency Bill set up a procedure to determine and manage mental defectives, in part through segregation in institutions, in 1913. This Act is notorious in British history as one which was intimidating and

		merciless, sentencing many to existences inside institutions. It was sporadic in its application, and slow to be implemented. It is worth pausing here to consider who was subject to the Act. The Act defined four grades of mental deficiency – idiots, imbeciles, feeble minded persons, and moral defectives (Walmsley, 2020)
Feebleminded	Feeble: Weak, infirm; deficient in character or intelligence; wanting in energy, force, or effect; dim, indistinct. Minded: Disposed (to do); having (specified) mind, as high, small	In the early 20th Century, the feebleminded were looked on as the most serious threat to society. This was partly because they looked exactly the same as ordinary people unlike 'idiots' and 'imbeciles'. The feebleminded were blamed for being abnormally fertile, giving birth to defective children, illegitimacy, venerable disease, criminality, pauperism, and drunkenness (Walmsley, 2020).
Solitaries	Solitary: Living alone, not gregarious, without companions, unfrequented, secluded, single, lonely, sole, kinds not living in communities; confinement, isolation in separate cell	There was a significant rise in solitary living after 1911 steadily rising from 1931 onwards. The most substantial rise progressed from the 1960s. In 1971, 17% of households within Great Britain contained only one person (Schurer, et al., 2018).

Moron	"adult with a mental age between 8 and 12;" used as an insult since 1922 and subsequently dropped from technical use (Harper, 2020).	This term was created by US psychologist Henry Goddard who created one of the range of IQ tests. He said morons with those with an IQ of between 51-70 (Rowlands & Jean-Jacues, 2017)
Ament		This word is not in The Concise Oxford Dictionary of Current English and therefor the researcher is surmising that this word has fallen out of use in the 20th Century.
Fatuity	Vacantly silly, purposeless, idiotic.	
Cretin	Deformed idiot of a kind found especially in Alpine valleys.	Cretinism is caused by the deficiency of iodine. The human body needs the mineral iodine to produce the thyroid hormone. In 1922 Switzerland distributed iodised cooking salt and lozenges for children, the result being the cessation of cretinism. Ionised salt, flour, rice, and oil are now distributed to more than hundred and twenty countries (Jacobs, 2020).

Table 13: 21st Century Dictionary Definitions

Word or Phrase	Dictionary Definitions	Commentary
Learning disabilities	A mental problem that people may have from birth, or that may be caused by illness or injury, that affects their ability to learn things.	‘People with learning disabilities are amongst the most socially excluded and vulnerable groups in Britain today. Very few have jobs, live in their own homes, or have real choice over who cares for them. Many have few friends outside their families and those paid to care for them. Their voices are rarely heard in public’ (Department of Health, 2001).
Mental handicapped	This term was not within the dictionary so changed to ‘Mentally handicapped’: (of a person) slow to learn or to understand things because of a problem with the brain (old-fashioned, offensive)	Since the last White Paper was published there has been better services for the mentally handicapped. Much progress has been made to close institutions and to put in place services in the community. There is still much more to be done (Department of Health, 2001).
Idiot	A very stupid person	‘… 20 years ago, if you got really drunk and did something stupid like moving a traffic cone you might spend the night in the cells and the police would be, like, you’re an idiot, go home, and now you get a caution and it would affect your personal rights’ (Levenson, et al., 2010).

Imbecile	Having a very low level of intelligence (old-fashioned, offensive)	‘People who were at one time considered extremely wicked may now be classified as cases of mental disorder. There can be similar problems when considering mental retardation or learning difficulty. The defect was envisaged as existing in its own right and as a cause for the need for care and control or in the case of a “moral imbecile” co-existing with vicious or criminal propensities’ (Bewley, 2020)
Feebleminded	Having less than usual intelligence (old-fashioned, offensive)	In today’s modern world the term feebleminded makes the reader feel uncomfortable. Though in the 19th and 20th Century this was a commonly used word around mental health and society as a whole (Kaplish, 2016).
Solitaries	A person who chooses to live alone	In Eve Baker’s book ‘Paths in Solitude’ she discusses how silence and solitude is hard to find in our modern world. She goes on to say that solitude has never been as popular as it is today with many people going on retreats (Baker, 1994).
Moron	An offensive way of referring to somebody that you think is very stupid	When a Parliamentary figure used the word ‘moron’ in one of their tweets it would seem the only people who protested were those within the disability community, though they were accused of being oversensitive and ‘silly liberals’ (White, 2020).
Ament		This word is not in the Oxford Dictionary and therefore no longer used in the 21st Century.

Fatuity	This term was not within the dictionary so changed to ‘Fatuous’: stupid	
Cretin	A very stupid person (informal, offensive)	Many believe that change can come about by changing the words we use. By no longer using such words as sufferer, victim, spastic, and cretin, this will cause society to respect the person with mental health problems and indeed see them as empowered and independent individuals (Cohen, 2014).

Appendix 2

Acts of Parliament 19th to 21st Century

Table 14: 19th Century Legislation

Act of Parliament	Commentary
Criminal Lunatics Act 1800	This Act was created by Parliament, at speed, after James Hadfield shot at George III. This allowed his imprisonment for life, no longer pleading insanity as a way of securing acquittal (Moran, 1985). This act formed the basis of the whole concept of criminal insanity, which may be why we still have places like Broadmoor in the 21st Century, which are technically hospitals not prisons.
County Asylums Act 1808	This Act was enacted to encourage the Justice of the Peace to build lunatic asylums for pauper lunatics. This was not acted on swiftly and many patients still ended up in prisons and workhouses (The National Archives, 2020).
Marriage of Lunatics Act 1811	This Act was extended to Ireland in May 1811, thus preventing any lunatic from marrying until they were pronounced sane by the Lord High Chancellor of Great Britain or Ireland. Should they get married this would be pronounced null and void (Irish Statute Book, 2020a).
Madhouse (Scotland) Act 1815	This act made provision for fee paying patients to be resident in private institutions (Barfoot 2009). The researcher hypothesises that this allowed the rich people in Britain, under the vowel of kindness, to lock away any relatives they were embarrassed by.
Criminal Lunatics Amendment Act 1815	Justice of the Peace now had the authority to order the making of inventories of insane people, this had to come with a certificate from a medical practitioner as to the state and condition of

	the lunatic or dangerous idiot. Again, this was all based on the assumed good judgement of the power of the justice (Bartlett 1993).
Irish Lunatic Asylums for the Poor Act 1817	Ireland passed an Act to allow the lordly tenants to direct and establish asylums for the lunatics who were also poor, thus ensuring they had shelter (Mauger 2012).
Pauper Lunatics Act 1819	By 1819 it had become apparent that the current system was no longer working and needed new legislation. The bid made by Wynn in the House of Commons was largely unsuccessful and many of his proposals removed or changed (Rae, 2014).
Lunacy (Ireland) Act 1821	“Act to make more effluent provision for the establishment of asylums for the lunatic poor, and for the custody of insane persons charged with offences in Ireland” (Irish Statute Book, 2020).
County Asylums Act 1828	An Act to amend the laws for the direction and regulation of county lunatic asylums. To provide for the care and maintenance of paupers and criminal lunatics in England (Roberts, 2020).
Madhouse Act 1828	This Act established the commissions model of governance for Middlesex (Staffordshire’s asylums records 2020).
Chancery Lunatics Property Act 1828	This Act was passed for the sale of mortgages of estates owned by people found to be lunatics. This act was passed between England and Ireland and controversy Ireland and England (Meanwood Park Hospital 2020a)
Madhouse Act 1832	This Act refined the previous Act of 1828 though very much of it stayed exactly the same. In section two of this Act the definition of the common words used were given, including the female and male. The doctors involved were also required to belong to the “fellow of licentiate of the Royal College of physicians in London” (Rae 2014).
County Asylums Act 1845 and Lunacy Act 1845	County lunatic asylums became compulsory along with the Lunacy Commission being established to take responsibility to regulate them (The National Archives, 2020a).

Lunacy Regulation Bill 1853	An Act to consolidate and amend the laws for the provision and regulation of lunatic asylums for counties and boroughs, and for the maintenance and care of pauper lunatics in England (The Asylum Journal, 2018).
Lunacy (Scotland) Act 1857	This Act started the rise in the public asylum system in Scotland to complement the Royal asylums. The board also appointed medical commissioners to supervise care and treatment of the insane at a national level (Asylum Geographies, 2012).
Idiots Act 1886	This Act was the first to deal with the educational needs of people with learning disabilities. It clearly distinguished between lunatics, idiots and imbecility (The Open University 2020).
Lunacy (vacating of seats) Act 1886	This Act received Royal Assent on 10th May 1816. This measure, which passed with little debate, laid out the procedure to be followed in cases where an MP was received or committed into or detained in an asylum, house, or other place as a lunatic (The History of Parliament, 2020).
Lunacy Act 1890	This professional development story began with the Lunacy Act of 1890, which caused professional crisis in psychiatry and led to interprofessional competition with nonpsychiatric medical services providers. To this end, psychiatrists devised a new political rhetoric,' early treatment of mental disorder', in their professional interests and succeeded in enacting the Mental Treatment Act of 1930 which reinstated psychiatrists as Masters of English Psychiatry (Takabayashi, 2017).
Elementary Education (Defective and Epileptic Children) Act 1899.	It became the duty of the local education authority to make suitable provision for the education of children exceeding the age of seven who were deemed mentally defective. (api.parliament.uk, 1899)

Table 15: 20th Century Legislation

Acts of Parliament	**Commentary**
Mental Deficiency Act 1913	‘An Act to make further and better provision for the care of Feeble-minded and other Mentally Defective Persons and to amend the Lunacy Acts. [15th August 1913]’ (Education England, 2020).
Mental Deficiency and Lunacy (Scotland) Act 1913	This Act established the General Board of Control. They structured the community-based services for mental defectives outside of the education system (Egan, 2001).
Education Act 1918	This Act widened the provision for special needs education. (UK Parliament, 2022).
Mental Treatment Act 1930	This Act made provision for the preventative treatment of developing mental illness by the setting up of outpatient clinics and extended facilities for voluntarily treatment. Certain cases may be placed under care and treatment without being certified. Opportunities by the general hospitals (municipal and voluntarily) in the handling of mental illness. More after-care and research into mental illness. The treatment of mental illness was separated from the Poor Law (The British Medical Journal, 1930).
Mental Health Act 1959	‘An Act to repeal the Lunacy and Mental Treatment Acts, 1890 to 1930, and the Mental Deficiency Acts, 1913 to 1938, and to make fresh provision with respect to the treatment and care of mentally disordered persons and with respect to their property and affairs; and for purposes connected with the matters aforesaid’ (Legislation.gov.uk, 1959).

Chronically Sick and Disabled Persons Act, 1970	“To increase the welfare, improve the status and enhance the dignity of the chronically sick and of disabled persons” Local councils were obliged to provide certain services for disabled people (Haves, 2020).
Mental Health Act 1983	This Act is the core legislation that covers the assessment, treatment, and rights of people with a mental health disorder (NHS, 2019a).
Disability Discrimination Act 1995	An act to make it unlawful to discriminate against disabled persons in connection with employment, the provision of goods, facilities and services or the disposal or management of premises; to make provision about the employment of disabled persons; and to establish a National disability Council (Legislation.gov.uk, 1995).
Human Rights Act 1998	An Act to give further effect to rights and freedoms guaranteed under the European Convention on Human Rights (Legislation.gov.uk, 2021).

Table 16: 21st Century Legislation

Acts of Parliament	**Commentary**
Mental Capacity Act 2005	This Act makes new provision for those who lack capacity through the Court of Protection. This Act connects with the Convention on the International Protection of Adults signed in the Hague in January 2000 and for connected purposes (Parliament, 2005).
Mental Health Act 2007	This Act is to amend the previous Acts; 1983, 2004, 2005 and section 40 of the Mental Capacity Act 2005, and connected purposes (Parliament, 2007).
Equality Act 2010	Article 14 of this legislation requires that all of the rights and freedoms set out in the act must be protected and applied without discrimination, for example if you are disabled (Equality and Human Rights Commission, 2021).
The Education Act 2011	This legislation makes explicit that it is unacceptable for educational attainment to be affected by gender, disability, race, social class, sexual orientation, or any other factor unrelated to ability. Every child deserves a good education, and every child should achieve high standards. (UK Parliament, 2011).
Mental Health (Discrimination) Act 2013	This Act makes additional specification about discrimination against individuals on the grounds of their mental health (Parliament, 2013).
Care Act 2014	This legislation sets out how adult social care in England should be provided by local authorities (Care Quality Commission, 2022).

Assisted Decision-Making (Capacity) Act 2015	The 2015 Act places the “will and preferences” of persons with impaired mental capacity at the heart of decision-making relating to “personal welfare” (including healthcare) and “property and affairs” (Kelly, 2017).
Independent Human Rights Act Review 2021	In December 2020, the Government announced an independent review to examine the framework of the Human Rights Act 1998 (Gov.UK, 2020).

Appendix 3

Medical Diagnoses19th to 21st Century

Table 17: 19th Century Signs of Autism; children and adults (Waltz & Shattock, 2004)

Main Signs of Autism	Other Signs of Autism	Autism in Women/Men[3]
Severe feeding and gastrointestinal problems	Difficulty in swallowing solids and frequent drooling	
Developmental delay	No normal play	
Not toilet trained	No meaningful interaction	
Oral-motor problems and non-verbal		
Nocturnal seizures		
Repetitive movements		

Table 18: 20th Century Signs of Autism: Children and Adults (adapted from Wing, 2010)

Main Signs of Autism	**Other Signs of Autism**	**Autism in Women/Men**
Pedantic or repeated speech	Delayed walking	More prevalent in men than woman
Non-verbal communication	Little facial expression and inappropriate gestures	Young men are socially inept towards woman
Lack of social interaction and ability to use rules and understand social behaviours	Lack of eye contact	
Repetitive activities and resistance to change	Over-sensitive to criticism	
Lack of motor co-ordination	Adults who behave childishly	
Unusual abilities in skills and interest	Lack of the normal interest and pleasure in human company	
Negative experiences at school	Lack of imaginative pretend play	

Table 19: 21st Century Signs of Autism in Adults (adapted from National Health Service, 2019)

Main Signs of Autism	**Other Signs of Autism**	**Autism in Women/Men**
Not understanding others' thoughts and feelings	Lack of understanding of social rules	Can be different between men and women
Anxiety in social situations	Avoiding eye contact	Women may be quieter, hide their feelings and appear to be better in social situations
Hard to make friends/prefer to be alone	Invading other people space/dislike of touch or closeness by other people	Harder to identify autistic women compared with men
Coming over as blunt, rude, or not interested in others	Noticing that details, i.e., patterns, smells, or sounds	
Hard to express own feelings	Over keen interest in certain subjects or activities	
Taking things very literally	Carefully planning things in advance	
Disliking change to daily routines		

Appendix 4

Table 20: A Checklist of Writing and Integrative Review (Torraco, 2005)

Before Writing an Integrative Literature Review
(a) What type of review article will be written (i.e., review of a new topic or a mature topic?). Is an integrative literature review the most appropriate way to address the research problem?
(b) Is there a need for the integrative literature review? Will the review article make a significant, value-added contribution to new thinking in the field? Organizing an Integrative Literature Review
(c) Is the review article organized around a coherent conceptual structuring of the topic (e.g., a guiding theory, a set of competing models)?
(d) Are the methods for conducting the literature review sufficiently described? How was literature selected? What keywords and procedures were used to search the literature? What databases were used? What criteria were used for retaining or discarding the literature? How was the literature reviewed (e.g., complete reading of each piece of literature, reading of abstracts only, a staged review)? How were the main ideas and themes from the literature identified and analysed? Writing an Integrative Literature Review
(e) Does the article critically analyse existing literature on the topic (i.e., is a critique provided)?
(f) Does the article synthesize knowledge from the literature into a significant, value added contribution to new knowledge on the topic?
(g) What forms of synthesis are used to stimulate further research on the topic? A research agenda (research questions or propositions), a taxonomy (or other conceptual classification of constructs), an alternative model or conceptual framework, or metatheory (theory that transcends the topic and bridges theoretical domains).
(h) Does the article describe the logic and conceptual reasoning used by the author to synthesize the model or framework from the review and critique of the literature?
(i) Are provocative questions for further research presented to capture the interest of scholars?