

RESEARCH PROBLEM/QUESTION:

“How can ND (neurodiverse) or autistic adults identify and disclose their conditions in a way that empowers their self-identity?”

SOCIOLOGICAL ANALYSIS PAPER:

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STRATIFICATION AND AUTISM
ANALYSIS PAPER: SPRING 2020

*“YOU ARE ALONE... I KNOW WHERE YOU LIVE... IF YOU’RE HAPPILY MARRIED,
I WILL MAKE SURE THAT YOUR MARRIAGE FAILS... YOU ARE SCARED, AND
YOU SHOULD BE... I AM AUTISM... YOU IGNORED ME; THAT WAS A MISTAKE.”*

AUTISM SPEAKS: I AM AUTISM CAMPAIGN (CIRCA. 2009)

Utilizing tools of threat-based rhetoric and human fear of the obscure, these (^above) lines were officially-broadcasted nationally by Autism Speaks not even twelve years ago to highlight the apparent urgency of this “invisible epidemic”; conditioning fears rather than spreading awareness, this societal narrative (ideology) of Autism has gained prominence and legitimacy within the beginnings of the 21st-century, partially due to the increasing social network/connection abilities, but primarily due to the dominant cultural perception of dysfunction which is a PMC amalgamation of perceived detriment to dominant subjective and false objective interests to a hegemonic production society/culture.

Tracing back to Asperger & Kanner et. al. medical study processes and their ideological separation between the human subject and observed behavior, individual conscious/societal collective intellect/knowledge regarding Autism has faced stagnation in its beliefs, ideas, and values, for undeveloped definitions have embedded themselves into the collective system. We are still stuck in the negative 1940’s deficit medical model view of conditions in which there is a meaningless goal of curing differences that haven’t even been pinpointed in the first place, a focus on “dysfunction” presented by deficit with the overarching goal of change-and-fix, implying damage, and brokenness.

Under Wright's construction of conceptual knowledge processes, these academics likely are not aware of the implications of their research and findings; stuck in a contradictory bubble, the PMC has indirectly created lasting social outcomes for Autistic adults by carrying out high paying information-based tasks for the industry owners. An example of this is the diagnostic material age in years/historical contextual circumstances, and the effects of initial studies/understanding of autism being exclusive to male children; up to this day, there is no diagnostic material based around presentation in females, and absolutely none for adults, making the medical diagnostic path for those missed in childhood long-term endeavors requiring extensive, independent research. They have made things as hard as possible for the community they're trying so hard to subjectively "cure", producing and organizing ignorance of any real objective outcomes or advancement.

In addition to the innate implications of status, power, and privilege put out by out-dated research models based on liberalism/merit myths, the information industry has evolved into that of a corporate hold materialized through knowledge monopoly and regulation of information flow-back, all in the name of exploitation and profit. In order to exist, they must be "legit"; these information network industries accept/remake rational mysticism for it is realistic, practical, and necessary for their interests; Autism speaks is the largest/most well-known corporations that represent Autism, but is just one influence in the industry apparatus which acts to limit inventive knowledge while promoting self-interested values to the public in order program society to create future values under their planned/directed organization. In order to ascribe alienation, Autism is deemed a disruption to that of the majority worldview/experience in economic, political, and ideological intellect/dimensions, valueless commercially. As a result, Autism is represented to society as an unknown fear/threat impacting families and individuals, thus, it is a worry that must be addressed ASAP.

Autism speaks only focuses on Autistic children and Applied Behavioral Analysis (ABA) practices to condition normalcy, though absolutely no attention is handed to the fact that these children grow up into adults. ABA is psychologically harmful to autistic individuals in its forced cohesion into a society not built for them, and once again highlights society's attempt to fix something into a mold that fits its functioning, rather than attempting to discover and accommodate a different reality. There is no interest in Autism itself as a condition or different neurology, it is

solely a topic objectified for subjective interest agendas in opinion, decision, and law-making, shaped by the control of specialized resources and research. If only 4% of Autism Speak's funds go to actual families/individuals experiencing Autism, what is the 22% spent on fundraising for? How about the other 74%?

The symbolic imagery of puzzle pieces is hated amongst the adult Autistic advocacy community and represents this stigmatizing ideology endowed upon them. It is a blatantly neurotypical design explicitly stating the perceived association between Autism not fitting society and the demand for a solution, something that they who are affected never wanted or asked for. Where there is esoteric obscurity, human fascination will follow. With fascination comes specialization, in tandem with corporate cultural addictions of control and changing of nature. Modern Autism narrative is a culmination of features including, though not limited to, increasing rates of diagnoses, its unknown origin, the level of perceived commitment to "solving" the problem, and the apparent disruption it inflicts upon the majority social practice/order. What is not being addressed in this contemporary consciousness is a contextual analysis of Autism as a condition in which the environment functions to disable (contrary stance to the innate deficit model), and the contributions of social evolution to the increasing discourse. Failing to humor the potential presence of Autism prior to medical/diagnostic definitions, society is at an imaginary war with something "taking their children away" at an alarming rate, getting worse as society moves forward.

Perhaps, this "epidemic" would be better understood within the context of capitalist society and the market values that it produces; prior to stigmatization of "mental disabilities", evidence of historic literature describing the diagnostic materials for Autism in people existed, widely considering the presentation as a creative-giftedness of a unique, peculiar mind. As culture moved towards a use-value model serving the ruling class, points of disparity became that of danger, as observed by the academics enlisted by the owners, and this difference signified dysfunction under the dominant flow of society. Researchers and industries alike push the agenda for discovering and stopping the unspecified causes for Autism's increased visibility/prominence rate, though they never address why these patterns may take place or what connected processes contribute. There is an ever-increasing need for postmodern critical reflection of the circumstances/context surrounding the topic, in opposition to the repeated creation of ideas based off of pre-existing versions within the

information apparatus (movement of resistance to modern conceptual knowledge production). Autism is most publicly seen within the realms of case studies for medical research or sentimentalized stories for the mainstream media, each carried out in equally dehumanizing manners. Fighting evolution of the species, this contemporary imaginative literature of Autism functions as a revisionist conventional representation of impairment/disability to feed the public, keeping the stories digestible and within the dominant ideology as to distract and redirect the working commodity classes, and to silence the Autistic community.

This social climate of subjective information has left Autistic individuals without the power to speak for themselves, for they have been cast aside in the general understanding/representation of their demographic. Those who feel entitled to “ally activism” believe they are poetically taking action with their individualistic, natural higher position of power as a means for defending the weak, non-functioning, a direct example of the values/relations/purposes the Autism industry has established in our culture. Continuation of person-first language (i.e. person having/with autism) reflects this polarizing reproduction of subhuman connotations, separating the self (research subject) from their experience, and has actually managed to evolve into reactionary social offense at identity-first language (i.e. “How dare you call them Autistic!”), despite its preferred use by the marginalized populations being addressed. We do not say, “with blackness” or “having gayness”; it’s dehumanizing and reaps human identity through labeling and assignment of an inevitable “burden” or trait carried by someone, telling them they will never be a whole, normal person, thus never leading a normal life.

Typically, the masses getting worked-up over presumed “correct” language are not even neurodiverse themselves, but ill-informed “normal people” practicing reification of programmed values in a false sense of knighthood; they must defend this helpless demographic, even if they have no actual knowledge-base on the condition’s experience and social narrative throughout history; even if they act as parasitic features in the contemporary climate of autism and disability discourse, working against the work of actual Autistic adults and advocates.

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RESEARCH COMPARTMENTALIZATION:



Academic Research

academic research regarding currently medically accepted autism knowledge.

- ❖ current medically accepted autism knowledge,
 - he likely learned that autism is a developmental condition that plagues a person for life;
 - that autistic people have problems with empathy, emotion, relating to others –
 - and the other things that many years of observing autistic people from the outside
 - without actually talking to them or considering their differences as valid, has yielded.

certainty that these peer reviewed articles -

- ❖ written and accumulated and reviewed in the basis of the pathology paradigm;
 - in ableism;
- ❖ in purely behavioural markers without consideration of *reasons* for behaviours;
 - in clinical observation settings with autistic people being looked upon like flies behind glass;
- ❖ assumption that being autistic is something wrong that needs to be rectified as early as possible
 - provided a solid basis upon which to make such a decision for his autistic child.

Academics

Academics don't understand or realise the outside implications of their work.

- ❖ Researchers tend to focus on a particular point of interest,
 - applying their particular area of focus, often in isolation to other fields of work.

But just because Researchers are in a bubble, it doesn't mean their work and their words are.

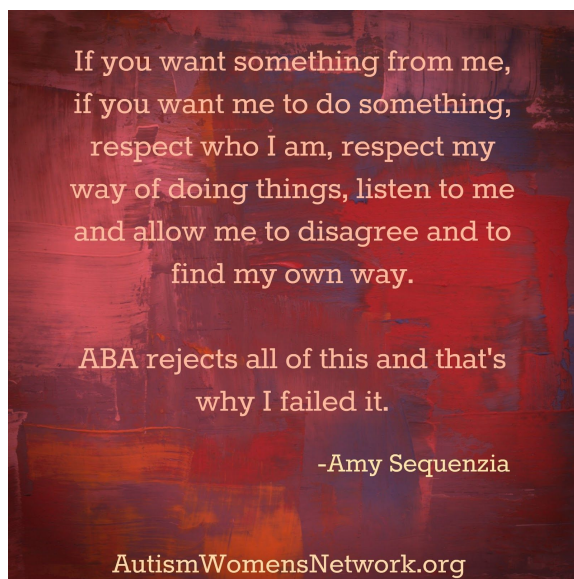
- ❖ The real-world application of what they do exists and all too often it exists in ways that many don't intend.
 - When research is picked up by the media for example (and usually leads to the word 'cure'),
 - or when some tiny aspect of a research paper is leapt upon and extrapolated beyond all belief.

societal thinking is strongly influenced by this

- ❖ It's where many of the myths and stereotypes around Autism and Autistic people originate from.
- ❖ This then can and does seep into Professional consciousness,
 - who in turn reinforce those stereotypes and myths into their practice and reinforce it in parents and Autistic people.

These are truly limited studies though, testing a narrow and non-autistic perspective.

- ❖ There are so many things that these studies don't show at all.
 - *What wasn't measured?*
 - *What is the importance of those things that weren't measured?*



Deficit Medical Model & Negativity

The deficit or medical model exists because

- much of human knowledge of the internal workings of the body is
- driven by the fact that once something breaks down,
- you can identify what it does by the other parts that don't work.

Person A can't communicate verbally

- ❖ = Person A has a communication deficit which must be fixed.

Person B shuts down or ignores emotive situations

- ❖ = Person B has an empathy deficit which must be fixed.

Person C doesn't do things the same as the others

- ❖ = Person C has a behavioural deficit which must be fixed.

This is where the argument between deficit and difference comes in.

- The deficits are decided upon without context.
- If you can't do A, then you must be B.

Adding Context & Positivity

But if you start adding in context:

Person A can't communicate verbally,

- ❖ *but can communicate efficiently and often better through other means*
 - ❖ = Person A communicates differently, this is easily facilitable.

Person B shuts down or ignores emotive situations

- ❖ *because they find they are emotionally overwhelmed by them and need to protect themselves from them*
 - ❖ = Person B experiences emotions differently and reacts accordingly.

Person C doesn't do things the same as the others

- ❖ *because they are doing things more efficiently based on their cognitive processes and in a way that keeps them happy, but harms nobody*
 - ❖ = Person C is behaving differently, let them get on with it if it helps.

If you think deficit, you think negatively;

- you focus on the things the person can't do,

→ you focus on how to fix what is supposedly broken.

If you think difference, you think positively;

- you focus on what they can do.
- What it doesn't mean is that the person does not need support,
- only that you are making their strengths a priority.

Out of the 1940's Way of Thinking

If you wind everything back to the 1940's and

- ❖ how Asperger and Kanner et al viewed and recorded Autism
- ❖ from their external perspective.
- ❖ You have to consider then that every piece of Autism research that has come after
- is using their work as the base material,
- is built on research that used their work as the base material
It all extrapolates out from effectively one source.

Much of what the Autistic community rails against is actually

- the narrow description of Autism as set in stone by those two.
- Many of the challenges to the narrative are against myths created and purported by Kanner (in particular)
- and those who have perpetuated his work.

Why is it that nearly a century later we're hanging off the words of someone

- ❖ who was, if you take the views of the Autistic community,
- ❖ actually very wrong in their description of Autism?

Why are we still diagnosing Autism in adults and children in the

- same ways and from the same criteria; and
- using a criteria which only identifies behaviours exaggerated by anxiety?

Not a Part, but a Whole

Currently we live in a world that thinks it

- ❖ Is right and proper that Autism is seen as a thing,
- ❖ a part of an Autistic person.
- ❖ A world that likes to focus on the Person First.

This is represented by Person First Language.

- ❖ Person First Language is designed to
- ❖ separate the person from their perceived condition.
- ❖ So with Autism it describes an Autistic person as
- ❖ 'having' Autism, or that
- ❖ they are 'with' Autism.

Using language like this creates

- the perception that Autism is a part of them,
- like an organ, or a limb,
- or more negatively a disease or a virus.

The separation of a person from Autism is

- something that is instilled in all of us Societally.

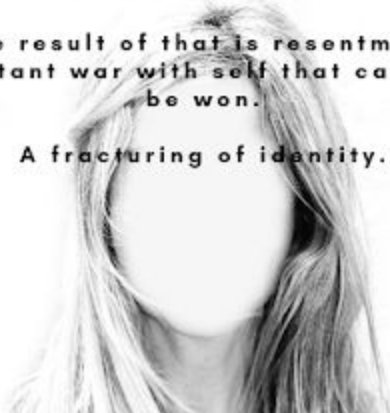
NT Conditioning & Language

**If we believe that Autism is only a part
of us, it instantly put us at odds with
ourselves.**

**There will always be a focus on a part of
the person that needs to be overcome, a
part which does not exist, so therefore
cannot be overcome.**

**The result of that is resentment.
A constant war with self that can never
be won.**

A fracturing of identity.



www.theautisticadvocate.com

The internal voice that we adopt

- ❖ from the world as children and

- ❖ onwards through to adulthood and beyond
- ❖ tells us that a part of us is broken.

There will always be a focus on

- a part of the person that needs to be overcome,
- a part which does not exist,
- so therefore cannot be overcome.

The result of that is resentment.

- ❖ A constant war with self that can never be won.
- ❖ A fracturing of identity.
- ❖ A negative feedback loop.

Self prejudice driven by language.

- Language which is driven
- from the top of the chain,
- to the bottom.

Autism Speaks (Autistica)

“What causes Autism...”

That age old question which is absolutely meaningless,

- ❖ but yet spend billions searching for the answer (and a cure),
- ❖ when we could be using that money to provide support and
- ❖ actually educate the world on what Autism actually is and what it isn't,
- ❖ instead of peddling the myths that are continuously reinforced.

their child ‘with’ Autism and how they knew something was ‘wrong’ with him,

- “I am autism... you ignored me. That was a mistake.”
- “Autism is naive. You are alone...”
- The Autistica rebrand
- No Autistic involvement at board level

Applied Behavioral Analysis

- ❖ That's what ABA does to Autistics: it advertises a “treatment” to make us “better”,
- ❖ to “recover” us from the “tragedy” of being neurodivergent, and
- ❖ “experts” praise this as if it is not abuse, while parents fight for insurers to pay for such abuse.

“It is not as bad as you think.”

- ❖ Yes it is. Putting children through unending hours of training, not allowing them to be who they are,

- ❖ forcing an experience of the world we Autistics can never naturally have, and
 - ❖ stating how not good enough we are to everyone else is pretty bad.

Autistic Narrative

We live under the pathological paradigm –

- ❖ driven with the aim of change and fix.

who we are can lead to

- ❖ Bullying,
- ❖ Isolation,
- ❖ abuse,
- ❖ mockery
- ❖ exclusion
 - all because people are afraid of the way we act,
 - the way we talk,
 - the way we do pretty much everything.

But if we do nothing, then the negative narrative continues.

- It becomes then a choice between continuing to hide and self-protect ourselves,
- or taking the leap to expose ourselves for the wider community's benefit
- ,based solely on thinking about the future;
- thinking about the lives of our Autistic descendants.

Dr. Sophie Vivian

Dr Sophie Vivian, who has a PHD in Ethics. Dr Vivian studies Neuroscience at King's College in London,

- ❖ with obviously a significant aspect of that covering Autism.
- ❖ often been horrified by the way that her Lecturers and the course material dismissed, stigmatised and dehumanised the very people they were studying and at points,
 - whilst offering definitions of what makes Humans, Humans, actively excluded groups of people (including Autistic people)
 - because of what they considered deficits, often based on very outdated and antiquated notions, that have long since been moved on from and re-understood.

Rhetoric to the effect that an out-group lacks any ability viewed as essential to humanity

- ❖ enables them be seen as subhuman, and,
 - this can in turn promote prejudice and violence (Cassidy et al. 2017; Kassin et al. 2014).



Authority & Inclusion

Autistic people and their supporters

- ❖ challenge the use of the term “disorder”,
- ❖ claiming it to be misleading,
- ❖ demeaning and
- ❖ an attack on self-esteem.
- ❖ Instead, many autistic self-advocates identify as “different”
- ❖ rather than “disordered”.
- ❖ The National Autistic Society (NAS) supports this notion of difference
- ❖ but also refers to autism as a “condition”.

According to this old narrative way of thinking,

- recognising that you are different,
- embracing that difference as an identity,
- clarifying that to the world,
- rather than suppressing it because of the way you are treated because you ARE DIFFERENT, is
- something we shouldn't do, because
- other people don't understand what makes you different and
- if they punish you for it, that's your fault.

This is basically a Professor of Inclusive Practice effectively encouraging Autistic people to Mask.

So if we stop saying we're different, the DVLA will treat us the same as everyone else.

If we don't embrace our identities, we'll get treated the same as everyone else.

If we just stay the same as everyone else, we'll get treated the same as everyone else.

If we Mask, we'll not get excluded from the herd.

Apparently that's how inclusion works.

Narrative Network

"The current culture of Autism is that Professionals decide what we need, Professionals train other Professionals, Professionals apply the services and then Professionals pat each other on the back and tell each other what a good job they've done."

- ❖ Media partners, funders, technology partners, ISRF – The Independent Social Research Foundation, content partners, etc.

It goes from being what appears to be a minor article,

- in a what looks like a small university publication,
- to having an enormous readership base and
- backed up and reinforced by prestigious places of learning and organisations.

Ted Cantel's Chain of Power

"In some cases, the views held about the members of another group are so exaggerated and misconceived that they become almost laughable. However, it is easy to dismiss them as the product of ignorant and closed minds as they can often be part of a social system which creates a hierarchical order, justifying discrimination in order to preserve the position of the superior group." —Ted Cantel

This chain of power shows how all the people (the lions) that need the power, the support, the education and the understanding, hold the least power.

The professionals and the Autism Industry drive this narrative.

Societal Narrative

as much as they comprehend they are talking to an Autistic person,

- ❖ they aren't really talking to an Autistic person;
- ❖ because the societal narrative of Autism,
- ❖ the negative narrative, has framed Autism in a certain way –
- ❖ and that way is not people who can type words into a keyboard coherently...

Every time a shooting occurs in the United States, what's the first thing the Media says?

→ "He was a loner, he was probably on the Autistic spectrum..."

In pretty much every country in the world Autism is legally

- deemed a Mental Health condition.
- Except it isn't a mental health condition at all.



Autism Industry's Hold on Society

There is an incredibly large industry that surrounds Autism.

- ❖ huge money to be made from it.
- ❖ Autism, the knowledge, understanding and even
- ❖ ability to provide supportive services is
- ❖ just not there

no adequate support for Parents

- they turn to the only salvation they have:
- The wealth of 'treatments', 'therapies' and 'cures', all offering ways to 'fix the problem'
- ❖ Schools buy into it.
- ❖ Health services buy into it.
- ❖ Charities buy into it.

The money starts flowing, the industry gets rich and richer.

- But who gets poorer and poorer?
 - Autistic people and their families.
- You were misled by Professionals.
 - Professionals who were misled by Experts.
 - Experts who were misled by hubris,
 - who set an arbitrary bar of what is 'normal,' and
 - measure Autistic people against it.

Experts who are funded by the Autism industry.

- ❖ An Autism industry that frames the negative narrative to fuel itself.

Societal Perspective

But it's also shaped by outside influences –

- ❖ it's shaped by decisions made by others that you adhere to and allow to shape you.

This cultural conditioning creates expectations of normality,

- that if you do not adhere to,
- creates a conflict with those around you, who are all also adhering to the same expectations.

So, if you are Autistic,

- the whole concept that everything about you is wrong is being drilled into you
- pretty much from the moment you are born,
- hence Masking.

Among diagnosed children though,

- ❖ a really common thing to hear from parents is that:
 - "I don't want my child defined by their Autism."



Education

This sticking out is ultimately announcing yourself to the herd –

- ❖ identifying that you are currently not part of it,
 - but want to be if the terms are right.
- ❖ More and more Autistic people and our friends and families need to
 - stand up in whatever way we can and shout the same message.

It always boils down to the same three things:

- ❖ Agitate, infiltrate, educate.

The second thing that needs to happen is that we need to understand why we are in this situation in the first place

- Why is our difference wrong to the rest of the world,
- why do they think the way they do about us?

The narrative against Autism is incredibly negative.

Something Different

If you've spent 20, 30, 40, 50 years or more suppressing yourself, living in fear,

- ❖ the sudden (it feels sudden even if it's been years in the process) emergence of the raw you
- ❖ (and I truly envisage it as a someone who has been flayed, skinless and open),
- ❖ the exposure to all those things that you have feared all your life,
- ❖ opening yourself wide to the herd as your true self,

- ❖ something different, someone different to them,
- ❖ is a massive psychological break.

Admitting to yourself and admitting to the world

- that you can't keep up with it, that
- forcing yourself to live like everyone else is slowly poisoning you, is decaying you,
- dissolving your whole being with every step,
- is a huge deal, it's the biggest deal.

The act of knowing,

- ❖ the act of starting to unlearn and unveiling the Autistic Identity,
- ❖ is a metamorphosis.
- ❖ If you are not strong enough of mind and soul and heart,
- ❖ it is almost impossible to get through.



Speaking our Story

The way we take in and process information through all our senses,

- the way that information is sorted and directed through our nervous system,
- the way our memories are stored and filed,
- the priorities our subconscious brain decides upon and
- the way in which that is expressed outwardly in our decision making,
- our movements through the world,
- our communication,
- our expansive consciousness,

→ our whole existence.

There is an intertwining through the negative narrative –

- ❖ the history of Autism and the language of Autism;
- ❖ how they are wrapped around each other and the
- ❖ lack of ownership of Autistic people of both those things.

The narrative of Autism is written by the hunters.

- ❖ The academics, the researchers, the charities,
- ❖ everyone but the lions (For those who have lost me, the Autistic people are the lions).

Everything the hunters write is shaped by outside perspective.

- It's all visual.
- They see behaviour and attribute reasons to it,
- they create their own story as to what Autism is.

They write the narrative.

- ❖ They control the narrative.
- ❖ They dictate where the narrative goes.

Nobody thinks to ask the lions...

- ❖ The narrative is harmful to Autistic people.
- ❖ It treats us as broken things.
- ❖ It talks about us as “they” and “them”.
- ❖ We're ‘othered’ completely.

Due to this the Identity that most Autistic people naturally adhere to,

- is either the one of the Mask where they hide in the shadows,
- or the one written by the hunters,
- which is still a Mask, just one created by someone else.

Not our Voice

Autistic people aren't allowed to speak for Autistic people,

- but non-Autistic people never seem to have to justify their right to speak on our behalf,
- even when we don't want them to...

Sharing our experiences with each other helps us to

→ understand ourselves much better and also to understand others perspectives.

We empathise with each other and gain a rounder worldview,

- ❖ a better understanding of ourselves and each other that
- ❖ makes us more qualified to speak about the Autistic perspective (singular and plural), than anyone who is not Autistic,
- ❖ regardless of how many books we may have read on the subject or how many external Autistic behaviours we may have observed.

the diagnostic criteria isn't actually Autism criteria at all, but one vast collective projection...?

Disabled by Environment

whether you choose to define yourself as any of those things or not,

- ❖ it's irrelevant, because you still are those things and
- ❖ society defines you and addresses you accordingly because of it.

We ARE disabled.

- Not because there is something wrong with us,
- but because we live in a world that chooses to treat us like we are broken and
- not adapt itself to accept us in it.

Everything I've written here is an example of how the world makes us feel,

not how Autism makes us feel.

Autism is not the Negative

As with anything there are negative aspects to Autism, for an Autistic person, but

- ❖ That does not mean that Autism has to be negative.

Suffering doesn't stem from Autism,

- it stems from complex co-occurring conditions,
- needs not being met sufficiently and
- the extreme anxiety generated by both.

The current narrative would have us think otherwise though.

- ❖ Nobody lives with Autism,
- ❖ you live with a person,

- ❖ an Autistic who just happens to do things differently to you;
- ❖ you shouldn't need to be reminded of that.

Framing Language

Language is powerful.

- ❖ Language frames thought.

So hear this language, frame your thoughts with this:

- Autism defines us **because** we are Autistic.
- Our identity is **ours**, it belongs to us and nobody else, whether we are 5 or 105.
- Look closely at yourself. What do **you** fear?
- Why are you afraid of **our** difference?
- Do **we** challenge **you**?
- Does it make **you** question who **you** are?
- Who are **you** to keep **us** from **ourselves**?
- Who are **you** to prevent **us** from embracing **our** identity?

Who are you?

Masking as a result of Invalidation

This person had been crippled by spending years Masking,

- ❖ fighting to fit in and trying to be 'normal' and
- ❖ tipping themselves over into Burnout so extreme, that
- ❖ at the age of 19 the only way they could see out, was out...

This young person was not 'suffering from Autism'

- as the mainstream narrative would have you think.

They were suffering from invalidation.

- ❖ An Autistic invalidation.

Autistic Burnout & Masking

What is it that's driving large numbers of Autistic children and young people

- to self-harm, to
- become so anxious and wound up that they refuse to go to school,

→ that they withdraw to their rooms?

What is it that forces many of them to

- ❖ go through this alone without seeking help from parents; and that,
- ❖ if they survive through this, sets them up for a lifetime of successive failures
- ❖ and periods of repeating this over and over again.

What the young person is referring to in the quote above is Autistic Burnout.

- ❖ What causes Autistic Burnout,
- ❖ aside from the stresses of actually living, is Autistic Masking.

why Autistic people Mask from an Autistic perspective.

- ❖ I've used words and phrases such as
- ❖ self-protection, hiding in plain sight, fitting in, normalising, camouflaging and passing...

why Autistic people Mask from a Non-Autistic perspective.

→ The answer to that is the word 'Invalidation'.

Masking Mental Health

“Beaten”, “Forced”, “Abused”, “Medicated”, “Suicide”, “Illness”, “Terror”, “Anxious”, “Stressed”, “Crisis”, “Half-life”, “Depressed”, “Burnout”, “Disappointment”

- ❖ This is just a handful of the words that were used by Autistic people when I
- ❖ asked them to identify the relationship between their Masking and their Mental Health.

Feeling like this IS safer, than not Masking.

“Autistic Pedigree” (aka, multiple mis-diagnoses) and all.

“What I thought was learning the social pleasantries everyone does to get along, I now know was making.

What I thought was giving up my childhood toys and habits as part of coming of age,

I now know was giving up my therapeutic stims.

Masking and mental health? Intimately connected.” – Anon

Suicide by Suppression

The running theme with these responses underlines the very things that I and many Autistic people talk about,

- ❖ that Masking and poor Mental Health are intrinsically linked;
- ❖ That suppressing who you are,
- ❖ suppressing your needs,
- ❖ suppressing the way you physically and mentally self-regulate is nothing but detrimental to us.

Autistic people die, according to research,

- on average, between the ages of 35 and 56.

Story after Story

***Autism Amazon* didn't know she was wearing a Mask**

- because she was not given the opportunity to find out that she was.
- Her whole life up until she was diagnosed was invalidated.

There is story, after story, after story, of people

- ❖ being turned away from diagnosis by Doctors, whose
- ❖ understanding of Autism seemed to stop being added to, shortly after the release of Rain Man.

There is story, after story, after story of

- ❖ children taking years to get a diagnosis (if they get one at all)
- ❖ by diagnosticians whose knowledge of Autism is reliant on the DSMs and ICDs of this world; and
- who have no wider experience upon which to base their decision.

There is story, after story, after story, of

- ❖ people who have been diagnosed with anything and everything except Autism
- (Bi-polar and borderline personality disorder diagnoses are really common in Autistic women BEFORE Autism is identified), because
- ❖ the Diagnosticians and medical professionals cannot join dots together and look at the bigger picture
- ❖ even when the patient puts the evidence in front of them, is jumping up and down and pointing at it.

Women internalize, boys, externalize (behavior-wise)

Higher IQ level in women is associated with a higher ability to mask;

- Compensatory-strategies; how do these girls manage to pass for normal, or get through so many years using certain skills that never get picked up?

Women with high intelligence and ND conditions are often called fakes and frauds of having functioning problems.

- Leads to strong feelings of imposter syndrome
- Self-identity feels unclear and confusing
- Females tend to have more social expectations to be faced with (more masking).
 - They feel a stronger sense of alienation and anxiety and tend to be taken advantage of quite regularly.

Misdiagnosis/diagnosis stacking is common which often results in wrong medications and more confusion/frustration.

- Very few assessment tools for young girls; NONE for female adults.
- There isn't awareness from medical professionals or support in the health-care system.
 - Definitions and criteria are based on dated studies of boys
- Need for equipment of knowledge and tools.

The Fracturing of identity

Autistic people die so much earlier than everyone else simply because our

- ❖ needs not recognised and understood as is
- ❖ reflected in the fact that Autistic people are more likely to die of injuries than any other cohort,
- the relationship between Autistic people and suicide as shown in the United States

It's so much healthier mentally to

- focus on the acceptance of self and to
- think positively in that regard, to
- seek strengths,
- to grow confidence,
- to respect yourself.

The Invisible Imposters

MASKING → different reasons, depth, and turmoil.

- ❖ After a while, you need to become different people just to survive for other people.

- ❖ Autistic people are actually overly-sympathetic and oftentimes get overwhelmed.
 - Old stigmas and definitions are dehumanizing and still prevalent.
- ❖ People don't need to be exactly like you, but they need to **believe you**.
 - Without trust, some may never feel safe to show their true personas and behaviors.

Language & Loneliness

The herd encompasses us, yet we're isolated, often lonely.

This fracturing of self, this separation driven by this narrative,

- ❖ This is what causes us to be alone.
- ❖ Detached from everything around us.
- ❖ Mask so hard in order to stay exactly where we are.
- ❖ This is what kills us.

All driven by language.

- ➔ Language created by the same people you have to fight against to get the diagnosis in the first place.

“Scattered persons in a very linear world.”

NEED development of belonging and a community; AGENCY & CONTROL.

- ❖ Is human value determined by the majority?
 - “Be yourself; don't try to be neurotypical, and find your strengths. Surround yourself with a support system.”
- ❖ “Perfectionism layered with multiple potentials can lead to stagnation and additional overwhelm.”

Identity Impact

certain terms and themes that you are familiar with around Autism and Neurodiversity,

- ❖ such as identity,
- ❖ Autistic Masking,
- ❖ Autistic Burnout,
- ❖ invalidation,
- ❖ Person First Language and Identity First Language,
- ❖ the impact of Society and the medical model on Autistic people

It is easier for some Autistic people to Mask themselves into an early grave, than it is to step off the cliff and fall into who they truly are.

Because they just don't know.

- ❖ Autism is who we are.

An Autistic Identity is integral to our well-being, physically and mentally, to our whole selves.

- Yet we are made to feel as though we have to suppress that.
- To go further we are actively told that our identity is wrong and broken.
- So we Mask and create and build new ones, false ones, imperfect replicas of ourselves.

Autistic people are different and

difference = threatening = fear = hierarchy = discrimination = dominance.

We stick out.

We disrupt, we cause PROBLEMS.

The fears that drive the main herd, do not drive us.

We move differently, we move ahead, or fall behind.

They trip over us.

Or at times we move right alongside each other and they turn to look at us and

we spook them.

Autistic Identity

So much of what I and so many other Advocates talk about:

- ❖ Language,
- ❖ Masking and Burnout,
- ❖ the history of Autism,
- ❖ the diagnosis,
- ❖ the near constant invalidation,
- ❖ this need for people to have a paradigm shift at all about Autism;

all leads, via a twisty, winding path through the undergrowth to one thing:

Identity.

“In this world it can feel like we have nothing to offer to make things better. Like many bad things are happening that are outside of our control. But if we know we are autistic, we have something pretty world changing to offer, simply by living without shame.

So stand alongside the children who have no say over whether they are publicly identified or not. The children who are currently experiencing the sympathy, the side eye, the misunderstanding. Who are experiencing people expecting less of them because of their diagnoses. Who are going to therapy to learn to be less themselves. Who are thought of as vaccine injuries and subjected to bleach cures. Who are talked about as less than human.”

Think about all the times you heard people talk about their little loved ones as a tragedy.

They have no choice. We do.

Stand up and say, this is what it means to be me, and

These are the things I need to survive and survive well.

These are the things I find hard,

these are the things I find easy, and

These are the ways I was harmed.

This is what autism means to me.”

Identity, not a Trait

If you are Autistic, one of the biggest parts of your identity is Autism.

Different Operating Systems



swap out Apple for non-Autistic neurology and Android for Autistic neurology.

- Both those neurologists pretty much look exactly the same.
- Both those neurologies effectively do exactly the same thing.
- Both those neurologies work completely differently and need a lot of support to be compatible.
- Are either of those neurologies better than the other?
- Not at all. They just do the same things in a different way.

This is the entirety of the human brain.

- ❖ So now do you see why we say we're Autistic from our heads to our toes?
- ❖ Our whole neurology,
- ❖ all our cognitive processes,
- ❖ our senses,
- ❖ the way messages are deciphered and sent from every part of our body
- ❖ to the cerebellum, the control centre,
- ❖ are all shaped and formed by Autism.

We're working on a different operating system.

- This is why the Autistic identity is so important.

Person First vs Identity First Language (PFL vs IFL)

Person First Language **V** **Identity First Language**

Person with Blackness	Black person
Person with Britishness	British person
Person with Womaness	Woman
Man with Gayness/Homosexuality	Gay man
Woman with Lesbianess/Homosexuality	Lesbian
Person with Blindness	Blind person
Person with Deafness	Deaf person
Person with Autism	Autistic person

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look at them side by side, you should instantly recognise

- ❖ how important identity is and
- ❖ how ridiculous it is to even think the other way.
- ❖ How empowering and self-pride inducing
- ❖ that language and
- ❖ that label can become if
- ❖ used in the right way.

The fact that Person First Language was

- ❖ created because people felt that they needed to be reminded that
- ❖ the person in front of them is a person and
- ❖ not a condition

The majority (not everyone) of the Autistic community prefer

- Identity First Language;
- "I'm Kieran, I'm Autistic. That's my person first."

Change with a Lack of Power

Due to the lack of power among Autistic people,

- ❖ Much of the efforts of those who seek to change things;
- ❖ who, for want of a better phrase, have woken up to the fact that things aren't right and
- ❖ that they aren't broken; are
- ❖ focused onto trying to change this narrative on social media.

"How dare you demean people with Autism, by calling them Autistic."

- Person First Language is used deliberately to
- separate a person from their state or condition, so as to
- keep the person framed at the centre.

Person First Language exists because

- ❖ 'Professionals' needed to be reminded that the
- ❖ person they are addressing is a person and
- ❖ not a diagnosis.
- ❖ Etiquette → ableism
- ❖ It implies something 'other'.

Autism is an Identity

Overall, we want it to be recognised that we are Autistic;

- ❖ as well as being a diagnosis,
- ❖ Autism is an identity.
- ❖ Our identity.
- ❖ Autism colours every aspect of our lives,
- ❖ it is how we perceive the world.

Our Autistic Identity is hidden under

- ❖ a Mask of society's creation.

Society's lack of acceptance forces us to

- hide in plain sight and then, when it identifies us,
- forces us to accept a narrative about ourselves
- of it's own creation.

The tool for this forced suppression,

- this oppression
- the language used to pin us down.

It Does Define Us

"Autism doesn't define you"

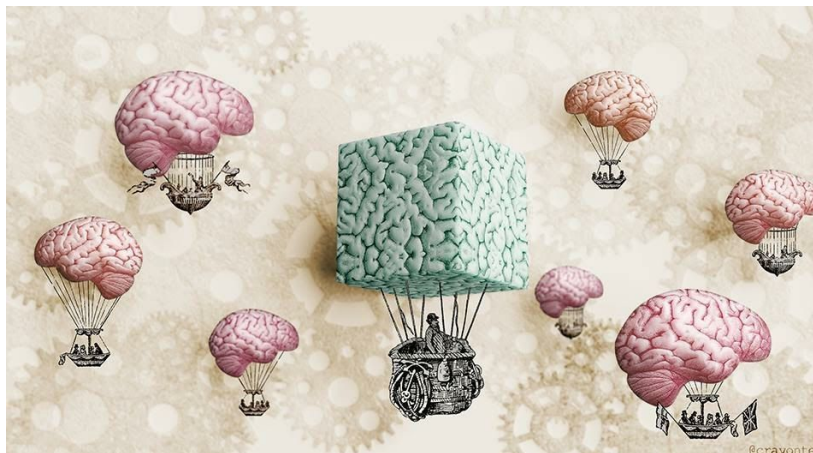
How can it not?

Autism DOES define us, because we ARE Autistic.

- As sexuality defines us, our skin colour, our ailments, our jobs, our traumas, our moments of elation;
- every aspect of our lives define us.
- But it defines us especially because
- it IS what makes us different from everybody else.

Positively so.

- ❖ But not according to the language of otherness,
- ❖ the language of separation.



Different, Not Less

Different, not less after all.

The key to all this is acceptance.

- Acceptance of self and
- acceptance of others.

The only negatives attached to it are those put there by

- broken and fix.
- Sustained by those that do not understand Autism nor
- the myriad of co-occurring conditions that hitch along with being Autistic.

Autism is owned by Autistic people.

- It's positive.
- It's an identity.
- It's our identity and it's so important.

SCHOLARLY LITERATURE RESOURCES:

as autism has become the subject of sustained mainstream media discussion, has been the **representation of the individual or family story where the condition has impacted on lives**

A frequent narrative that was thrown up by the Google search concerned the **reporting of medical investigation into the possible causes of autism, along with the increased rate of diagnosis and the potential treatments available.**

The following, from my alert of 5 May 2007, was typical: It's the fastest growing developmental disability in the US, autism. One in 150 kids now have the neurological disorder and doctors are not yet clear on what causes it and there is no cure but a treatment now done here in Rockford is making significant strides...

This narrative is a blend of features – the increase in diagnoses, the unknown origin, the commitment to tackling the problem, the hope inherent in the new development – that then leads on to the specific news story. Within it, autism is both a pressing issue of current concern and a somewhat abstracted, unsourced, alien phenomenon, something that seems to have come from nowhere.

autism emerges from these multiple daily stories as a worry, an unknown fear and threat, that needs to be addressed as soon as possible

This ‘fact’ of autism as a worry and a fear is possibly best seen as an example of the ways in which disability disrupts the majority, non-disabled, worldview.

As numerous critics and theorists working within disability studies have noted,

the disabled body or exceptional mind works to demand explanation or invite correction. Its status as a difference from the norm is itself a ‘worry’, a clear embodiment of what can and does ‘go wrong’.

Autism appears as a **peculiarly silent and pernicious version of this disruption, an object difficult to identify and too problematic in its range (from the non-verbal to the garrulous, from severe sensory and environmental experiences to small character ‘eccentricities’) to regulate precisely.**

One possibility that always seems to provide unease is that the spectrum of autistic subjectivity might be as wide as the spectrum of non-autistic subjectivity. This inability to locate autism properly is common to many of the news stories in which it features, though played out in different forms

Narrative Prosthesis: Disability and the Dependencies of Discourse, David Mitchell and Sharon Snyder posit the idea that **the imaginative or fictional narrative that represents dis-ability often offers a revisionist version of more conventional accounts of the place of impairment or disability in society.**

Noting that their book ‘analyzes literary works as commentaries on the status of disability in other disciplines’, they go on to assert that **‘imaginative literature takes up its narrative project as a counter to scientific or truth-telling discourses. It is productively parasitic upon other disciplinary systems that define disability in more deterministic ways’**

representation of the condition within cultural narratives

Equally, fictions repre-senting autism can be correctives to the kind of ‘deterministic’ accounts of which Mitchell and Snyder speak, and ***release the condition from its often pejorative subject positions in, say, the case studies of medical research or the sentimentalizing narratives of mainstream news media.***

Rather, we might feel that such narratives have overlaid the condition not with understanding but with the complex desires of a society that wishes to be fascinated with a topic that seems precisely to elude comprehension. Certainly, the majority of the analysis that follows will be of stories, accounts and versions that create an idea of autism rather than try to reflect one, and in seeking to explain why this is so there is a real need to look at the place of the condition, and disability more generally, within contemporary culture and the stories we tell ourselves.

But we are novices when it comes to thinking how specifically cultural versions of disability influence their various subject matters, for all that such versions are increasingly popular.

Yet disabilities of all kinds continue to be subjects that many would sooner not discuss in the public arena, because of the threat they are perceived to display to ideas of bodily or mental integrity. These are still topics that can inspire fear. At the same time, much of the force of this study’s critical focus stems from the belief that autism is in some way a condition that has acquired a particular and specific emphasis, and indeed popularity, in the very contemporary

period. It is, we might say, the condition of fascination of the moment, occupying a number of cultural locations that reflect a spectrum of wonder and nervous-ness – the allure of potentially unquantifiable human difference and the nightmare of not somehow being ‘fully’ human.

autism is prone to representations that vary from the seemingly hard business of scientific enquiry to the more fanciful accounts of speculation

respects the idea that autistic presence contains its own logic and methods, and that these have to be understood, and if possible understood from within, if a full autism.indb 517/04/2008 15:17:50 Representing autism idea of the place of the condition in the world is ever to be gained. As we shall see, these expressions can be found across a range of cultural productions, from written life stories to the visual arts, and – more and more frequently – in the cyberspaces provided by the freedom of the internet, spaces that have become crucial to autistic expression.

Such debates, about the integrity of human worth and the ‘quality of life’, are seminal to our thinking about autism.

In a contemporary world of vaccine scares, differences of medical opinion and discussion of an autism ‘epidemic’, the condition occupies contested ground in an arena in which it appears as if little is agreed upon. It is precisely because of such uncertainties that the cultural narratives that depict autism require analysis more than ever, because they function at a time when what is known about the condition is open to debate. In the free world of narrative interpretation, autism can, and does, become an open topic for representation, in part because of the lack of scientific consensus on the condition

Frith’s *Autism: Explaining the Enigma* has a chapter entitled ‘Beyond enchantment’, which analyses classic fairy tales such as *Snow White* and *Sleeping Beauty*, as well as Russian ‘blessed fools’ and Arthur Conan Doyle’s characterization of Sherlock Holmes, as possible cultural forms by which encounters with autism before twentieth-century medical pronouncements were mediated.

term ‘parents and professional’ writing on autism, with publishers specifically targeting family and carers as a market. To pick just a single title, Nancy D. Wiseman’s 2006 *Could It Be Autism? A Parent’s Guide to the First Signs and Next Steps* is typical of the hundreds of books that seek to educate and advise parents concerned about their children’s development.

The narrative that surrounds the ‘catastrophe’ of a parent discovering their child to have autism is one of the most prevalent in contemporary culture, whether found in fiction or the non-fiction exemplified by Wiseman’s book. In such texts, autism is often portrayed as a condition open to treatment and remedy precisely autism.indb 717/04/2008 15:17:50 Representing autism because it is seen to have a base psychiatric component that allows for intervention and change. The notion that a child with autism can be ‘saved’ from the condition follows as a logic that says more about social fear and desire than it does about neurobehavioural difference.

Despite an obvious focus on the wide idea of disability, Mitchell and Snyder’s *Narrative Prosthesis* contains more index entries on Nazis than it does on cognitive impairment, and though that text calls for a greater emphasis on the issues of neurological (as opposed to physical) difference, their follow-up monograph, *Cultural Locations of Disability* (2006), has little to say about cognitive exceptionality gener-ally, and has a single paragraph on autism in a book of some 250 pages. The centrality that the body occupies in contemporary disability studies that focus on narrative is nearly ubiquitous. Mitchell and Snyder’s 1997 edited collection of essays has *Discourses of Disability* as its subtitle, and is full of an attention to the subject of ‘human disability’, but its main title – *The Body and Physical Difference* – is a clear indicator of where its emphasis lies.¹³ In a similar vein, *Disability/Postmodernity*, Mairian Corker and Tom Shakespeare’s 2002 collection of essays that uses a variety of poststructuralist approaches to the questions surrounding disability studies, has as its subtitle *Embodying Disability Theory*, in a clear nod to the primacy of physical issues thought to lie at the heart of the subject.¹⁴ Seminal figures in the field such as Lennard J. Davis and

Rosemarie Garland-Thomson, who have produced excellent influential studies that have shaped the emerging forms of current critical dis-ability scholarship, often make the linguistic slip whereby 'disability' in their writing comes to mean physical impairment.

It is increasingly clear that many conditions of cognitive or neurobehavioural difference, autism included, are produced to one degree or another by the physical structuring of the brain. For all that we need to think of autism, or conditions such as attention deficit disorder (ADD) and attention deficit hyperactivity disorder (ADHD), as having central manifestations that are behavioural or produced by the environment, recognizing the difference inherent in neurology is vital and the subject of much medical research. And, of course, seen in these terms the brain is as physical, if not as markedly visible, a part of the body as a limb. Indeed, it is intriguing to think of the seeming indifference paid to autism by dis-ability studies scholars as being a point about visibility, considering the autism.indb 817/04/2008 15:17:50 Introduction centrality of such a concept to the idea of disability as a whole. It does appear impossible, given the evidence, not to construct the ignorance and evasion of the topic in such terms. Equally, the life stories of many of those who have autism return to the frequent observation that one of the manifestations of the condition comes in the way in which it produces a need to control the body; the way the autistic body functions in space is part and parcel of what autism is and how it works – autism is a condition with a strong physical component.

Public interest in questions of health and disability has never been stronger, and as a consequence cultural forms across a range of media currently produce a never-ending stream of narratives and images that both reflect this interest and generate its forms.

An Anthropologist on Mars, Oliver Sacks writes 'Autism, clearly, is a condition that has always existed'.¹ His comment is the product of a life spent as a neurologist caring for those who are cognitively different, and his relationship with autism has led him to investigate the historical record in a search for cases that, as a clinician, he might recognize.

Possibly autism will experience a fate similar to that of schizophrenia, once thought of as a possible spring of creativity and wonder, but now more commonly related to media stories about crime or state health policies.

The scientists hold up their hands autism.indb 20717/04/2008 15:18:12 0Representing autism and admit to a lack of knowledge about the cause or the various forms the condition might take, and this coincides with the idea that autism appears to be everywhere, exploding in an epidemic that is about people and yet that also seems, even in its most general formations, to be somehow easily apprehended as a metaphor for a version of the present, as some kind of cultural and social mirroring. The central point to be made about such a linkage is that it will create very real dangers if the conception of autism as a metaphor floats completely free from the actuality of the condition itself. In the suggestion that we are all, in some way, autistic, or that the term might be usefully applied to other contexts (listening to the radio while working one morning, I heard adolescence described as 'temporary autism'), there is a chance that the word will become meaningless. For this to happen at a point when so much is still unknown about the condition would be a disaster, and yet there have been many times during the research for this book that it has seemed to me as if it is a process that is already occurring to some degree.

Few of the narratives that have come in the preceding pages have had much to say about cause, and this is even true of the MMR stories, where an idea of a cause has provided the platform to discuss what might come next. On occasions, for example where a revelation about the supposed origin of the condition carries some sort of shock media value, a debate about autism's cause will briefly animate news narra-tives.

of course, the suggestion that diet is all-important, that the connection between digestion and the brain in the growing child is a vital and vulnerable one in which autism somehow waits, like a kind of predator, to exploit the wrong connections. Possibly what unites all these scenarios is an idea of toxins, of the problem being some form of poison, be it physical and somatic or environmental. At times, we seem to worry that we cause autism by living the wrong way.

So, identifying causes might be about pinpointing the problem, and of course, such an idea fits with the broad medical notion of dysfunction. Medical research will continue to look for what might be supplemental or lacking in the autistic brain and, in all probability, all sorts of progress will be made. It still would be productive, autism.indb 20817/04/2008 15:18:13 Conclusion 0however – even if it seems utopian – to wish for an idea of cause that did not see it as aberrant or an anomaly, but rather as a consequence of human diversity. Because, of course, the conception that the cause of autism is an aberration can lead only to the desire for a cure, for something that rectifies the mistake. This study has seen an extended idea of ‘curing’ at work in all manner of narratives, from the ‘compensation cure’ of savantism to the devotional love of a parent producing miracles. Whether overt or implicit, curing autism seems to be something we cannot help but want. It is, in this manifestation, something like cancer, that other great medical demon of our times. Like cancer, autism is often seen as a remorseless attacker of innocents, a destroyer of lives and families.

They challenge the viewer’s perception of what autism is, and they voice the demand that those with the condition have the right to shape their own lives.³ As we have seen, set against the arguments of the advocates are other communities, usually parents, who see autism as a condition that afflicts their children, and that causes pain, illness and fear. For this community, curing is paramount and an obligation, and the research funding capability of an organization such as Autism Speaks is a reflection of the powerful belief with which this argument is held.

The lack of understanding about autism among we so-called ‘normal’ people is one of the major causes of the unhappiness and isolation of those affected by this potentially devastating condition. It would be wonderful to think the NAS’s campaign could change attitudes.⁴In

Treating Autism. Lara Hawkings, a spokesperson for the group, noted: ‘Hope for people with autism does not lie with celebrity endorsement and a pretence that autism is normal but in the torrent of medical research that is pouring out of the United States’.

We might care less about causes if we knew exactly what it means to live with autism. We might be less sweeping in our assumptions about cures if we had a sense of what the condition entails. Conversely, we might better understand the links between autistic and non-autistic humanity if we approached the subject with less fear.

if we see more autism around us than at any time in history, and if we think of the consequences of knowing it to be a lifelong condition, then we can also admit that we have a greater opportunity for dialogue than has ever existed. Listening to those with autism has never been a more available option, and it is one that those who are in the business of making cultural representations of the condition need to take up

a narrativized idea of autism is Majia Holmer Nadesan’s *Constructing Autism: Unravelling the ‘Truth’ and Understanding the Social* (2005). With a viewpoint grounded in medical sociology and health studies, Nadesan points out that, whatever the nature of its biogenetic origins, autism needs to be seen as a condition that rose to prominence in the twentieth century because of specific social factors that aided its identification and understanding. The practices and institutions that thus dictate such issues as diagnosis and treatment emerge not from a neutral space of scientific or medical knowledge but rather as a consequence of the ways in which science and medicine find themselves implicated in social debates. For Nadesan, autism, the idea of the spectrum and of Asperger’s syndrome and so-called ‘high functioning’ autism, are all part of a crisis surrounding ideas of child development.¹⁶ In this last emphasis her insight fits the concerns of a number of the cultural texts I will look at in this study, where the idea of what constitutes autism is frequently explored through the figure of the child, and in which a notion of a personal future is consistently stressed.

The label ‘autistic’ today is not necessarily always a description of an individual with a clear neurological difference. It is, in many ways, and as I shall explore fully in the pages that follow, a word that is increasingly used to describe both people, and indeed situations, as generically ‘odd’ or even dangerous.

So, any act of human behaviour that might be seen as obsessive, or concerned with difficulties in social interaction and expression, is increasingly thought of as 'autistic'. Equally, through processes of a retrospective diagnosing, historical and contemporary figures – from Isaac Newton and Albert Einstein to Andy Warhol and Stanley Kubrick – are 'outed' autism.indb 917/04/2008 15:17:50 10

Representing autism individuals with autism through a reading of their characters and actions.¹⁷ Psychiatrist Michael Fitzgerald is the writer most associated with this phenomenon. In books such as *Autism and Creativity* (2004) and *The Genesis of Artistic Creativity* (2005), Fitzgerald analyses a myriad of philosophers, writers, artists and musicians, through a variety of criteria, before arriving at a diagnostic pronouncement: 'George Orwell meets the criteria for Asperger's syndrome', or 'It would appear that Kant displayed the criteria for Asperger's syndrome'.¹⁸ There is a clear danger in such processes, namely that the word and all it implies can be diluted to a point where its meaning becomes increasingly difficult to pinpoint; however, it should also be recognized that any desire to see autism as a viable, and not uncommon, part of the human spectrum requires an understanding of the condition that moves beyond a scientific or medical categorization. And, given that there have always been people with autism, there is an arguable logic to re-reading narratives in search of those people from periods before the condition had any diagnostic criteria or public dimension. The difficulty lies in establishing how extending an idea of autism that respects the nature of the condition might find expression at a time when it also has to be read in terms of its increased use as a metaphor, and how it interacts with the knowledge prevalent at a time before the category of autism itself came into being.

autism-related stories on the internet, I found an article on toxins that linked autism to the terrorist attacks on the US of 11 September 2001, and another protesting against the location of a new all-Ireland centre for the study of autism in Northern Ireland.³ Both pieces were, in their own ways, commentaries on specific issues, but each also practised the kind of cultural linkage which is becoming increasingly common whenever autism.indb 2717/04/2008 15:17:51

Representing autism autism is discussed. 'America has Asperger's', historian Niall Ferguson wrote in the *Daily Telegraph* in May 2004, in one of the most explicit examples of this. 'You may not yet have heard of Asperger's syndrome', Ferguson wrote, 'But you can be sure that someone will sooner or later offer it as an excuse for his own bad behavior, for it is the height of hypochondriac fashion in New York'.

its status as a contemporary metaphor is undeniable. There is no particular specificity in these examples. Rather, there is a process of creep, through which a perceived association between autism and a general notion of difference is articulated, or the condition starts to parallel other central news stories because of its seemingly inherent newsworthiness. Odd, strange, difficult and even dangerous (increasingly autism and Asperger's feature in the media profiles of those accused of a crime – the claim that Virginia Tech killer Cho Seung-Hui was autistic is only the most high-profile example),⁵ autism is diffuse in these commentaries, a floating term working through loose generic association.

The degree of awe savant talents produce is matched by the idea that these skills act to compensate for the disability with which they are associated. Hence the common attachment of the word 'idiot' to 'savant', to designate this double aspect of ability and impairment. The term 'idiot savant' itself dates from 1887, when John Langdon Down, discussing his own patients in his book *Mental Afflictions of Childhood and Youth*, used it to describe those individuals given to prodigious feats of memorization. Though the phrase has now arguably become outdated, it nevertheless retains a certain popular usage, still turning up in magazine articles and on television. Looking back less than twenty years, we can see that the term had a clear academic use as well. Michael J. A. Howe's 1989 study *Fragments of Genius* has, as its subtitle, *The Strange Feats of Idiots Savants*, and in his introduction Howe not only explains the processes by which he came to use his chosen terms, but also gives an indication of the place autism occupied in relation to ideas of the savant at the time of his writing: 'Idiot savant' is the term that has most frequently been used to designate mentally handicapped individuals who are capable of outstanding achievements at particular tasks, but scientists reporting on these people have also introduced a number of alternative labels. These include 'talented imbecile', 'parament', 'talented ament', 'retarded savant', 'schizophrenic savant', and 'autistic savant'. Some authors have used lengthier descriptive terms, such as 'children with circumscribed interest patterns'. Others write of the 'savant

syndrome'.... Whatever the chosen forms of words, it is important to be clear that whilst having some kind of descriptive terminology is undoubtedly useful for broadly classifying people, any suggestion that the chosen term can also serve to explain their attributes should be resisted. It would be unwise, for instance, to make any explanatory inferences when terms such as 'autistic savant' or 'schizophrenic savant' are encountered. They are useful descriptive labels but really no more than that.¹ Howe's the book feels as if it comes from a different era. Phrases such as 'retarded', 'limitations', 'feeble-minded' and 'backward' litter his prose, and his case study and inquisitive method convey the clear feeling that the subjects of which he speaks are human curiosities, only just falling short of being freak-show exhibits: One of the weirdest reported cases was that of a man who, although profoundly retarded to the extent that he could not even dress himself autism. indb 6617/04/2008 15:17:53 Idiots and savants or speak a single word had the curious ability to spin corrugated metal dustpans and other objects on the index fingers of either of his hands.

It is well and good that such changes are made, of course, but, as we shall see, in popular representations of autism the idea of the idiot and simpleton remain in certain forms, and certainly, the notion of compensation, the ability/disability split, is strongly featured in texts that portray savants.

As a condition that does not automatic-ally signal its presence, and unlike certain other disabilities, autism can go unnoticed, inhabiting invisibility. Even the most pronounced cases of autistic behavioral differences do not involve a continual visual signification of disability. Individuals with autism can, and do, involve themselves daily in activities in which their difference goes unrecognized, a form of passing in the majority world. At the same time, autism can provoke sudden, seemingly inexplicable, behavior that is highly physical and visual. From tantrums to self-harm, and from playful vocalization to pleasurable acts of physical repetition, autism can be an eruptive force, and – as a consequence – one that invites the gaze of onlookers. And, of course, in thinking through the issues of such gazing, we realize that the processes of looking for and at autism combine.

There is an inherently visual dimension to the ways in which disability is understood and, even with the complexities of the condition's presence, autism is no exception to this rule. At the same time, there is another kind of visual process with regard to autism, one more difficult to categorize. Looking at someone with autism can be deeply personal, in specific ways.

Seeing is vital in any consideration of autism. As writers such as Donna Williams have shown in articulating their lives, the visual and perceptual difference is often a key element in the ways in which autism manifests itself, and much medical research has focused on understanding the ways in which the condition influences looking at and processing images. For anyone outside the condition, seeing is initially what you do: you look for it and its signs. If the person with autism is close to you, someone you know well and have known for a long time, you also look for times when it appears not to be there, and for the subsequent ways in which it has made itself familiar. If it is a stranger you encounter, you look for the ways in which it makes autism. indb 10517/04/2008 15:17:56 10Representing autism itself known. And then, when you know, when you're in the afterworld of knowledge, having read all the books and websites, it is common to watch. Watching here is both exceptional and normal. Personally, I found that in a relationship where at times there could be little or no overt communication there seemed no problem with a kind of prying, despite all I know and feel about privacy. So it became a habit to spend long periods of time watching a person who didn't watch me and seemed to care little about my watching. Watching is less angst-ridden than seeing. It is long term, about learning when seen positively and constructively, and it is frequently pleasurable and funny – I play games with my son and his sightlines, me trying to make him catch my eye.

there is a swirl of comment and debate about the causes, manifestations and treatments of autism, but in the midst of the various arguments, it is wise to remember that it is properly understood at a general level as being a lifelong condition. 'Autism', Uta Frith noted in *Autism: Explaining the Enigma* in 1989, 'does not go away'.¹ It is, in the more

technical language of Laura Schreibman, a 'form of psychopathology ... characterized by a unique constellation of severe and pervasive behavioral deficits and excesses' (emphasis added).² Pervasive and present, autism is not something one grows out of. And yet, given that this is the case, contemporary cultural fascination with autism nevertheless relentlessly focuses on the figure of the child when seeking to explore what autism is and what it might mean.

Even though it is obvious that children with autism will become adults with autism, the sense that the condition somehow affects children more than adults is itself pervasive.⁴ Again and again in contemporary cultural narratives it is the child who carries the weight of what we wish to say or think about the condition, and it is through a focus on children that autism is increasingly being understood. 'This disease has taken our children away. It's time to get them back', says the US Autism Speaks website, in one of the clearest statements of this effect.

Autism, it appears, can be understood best when seen in terms of the male character, and while its presence within females can-not be denied, it seems more difficult to map an idea of the condition on to the generalized sense of what we believe girls and women to be. Given that two of the most high-profile figures with autism – Temple Grandin and Donna Williams – are women, this appears especially counterintuitive. But, as we shall see, the urge to discuss autism by seeing it in terms of relationships between men is very strong

In the hard pragmatic world of disability charity fundraising, a focus on children is far more effective than one on adults (and this is especially true if the disability is cognitive). More revenue is generated if autism is 'marketed' by charities as a condition that mostly affects children than if the stress is on autistic adults. Hence the comment by Autism Speaks noted above, where the emotional language is not only a statement of the foundation's beliefs but also one carefully directed at would-be donors. In a similar vein, it is worth noting that the National Autistic Society in the UK has had its present title only since 1982. In the twenty years since the Society's formation in 1962 to that 1982 date, all versions of autism. indb 14017/04/2008 15:18:03 Boys and girls, men and women 11organization's title included the word 'children'. But the change in title and the overall focus on children also have to be seen as an indication of the contemporary nature of interest in the condition. Historically, much of the energy involved in autism awareness has come from parents seeking to highlight the conditions of their children, and it is precisely the fact that a generation of children with autism, born in the 1960s, are now adults that have caused a shift in the thinking surrounding nomenclature. The two girls in Jane Bown's photography on the cover of this book, for example, will now be well into their forties

it carries special resonances in the depiction of families, where the figure of the autistic child is often made meaningful, in a narrative sense, by the way in which it initiates drama or insight in the world of the adult parent. The portrayal of children with autism produces much of the adult meaning of autism, and there is no doubt that this is, in a large part, due to the specific nature of the condition as it exists in the public consciousness at this time.

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Facebook communities/groups:

This is Autistic Culture:

private group > 6,686 members

"A GROUP FOR US: This group is a place primarily for Autistic individuals. ***If you are an allistic loved one or ally you're welcome to join, listen and learn, but know that this is not a space for you and your needs.***

BE RESPECTFUL: While we are all autistic, ***our experiences are very different. Listen with respect and withhold judgement.*** If you behave in a transphobic, ableist, homophobic, racist, sexist, classist way you will be removed.

BE OPEN TO LEARNING: You may not be ***up-to-date on acceptable language, but if you are corrected be open to learning.*** Please ***use identity-first language, refrain from functioning labels and puzzle-piece imagery.***

SUPPORTING ABA IS NOT TOLERATED: ABA is abusive. ***Any support for ABA will be not tolerated in the group*** and will result in muting or blocking, depending on your actions.

NO ROMANTIC SOLICITATIONS: Please ***respect your fellow group members' boundaries.*** Ask before you send messages to people you don't have an established relationship/friendship with, and please don't hit on strangers.

"IS THIS AUTISTIC CULTURE" DOES NOT MEAN "ALL AUTISTS RELATE TO THIS": It also ***doesn't mean "autism caused this"***. It's just a ***format by which we find people who can relate to us. It's fine to disagree but be mindful of the way you express this*** because it can be invalidating, especially if the post is about another marginalized group you don't belong to.

NO GATEKEEPING: Not everyone can access a diagnosis, or wants to be formally diagnosed. ***We accept and welcome self diagnosed autists here.***

PLEASE INCLUDE IMAGE DESCRIPTIONS: For folks using ***text to speech technology, images will be skipped over entirely.*** To ensure ***this space is accessible*** please ***include an image description.*** If you are unable to write one someone in the comments will most likely volunteer, and you can copy and paste and update the post.

INCLUDE TRIGGER WARNINGS: ***If your post deals with triggering content*** such as COVID-19, assault/abuse, self harm or suicide, ableism (internalized or not) and other forms of oppression, sexual content, death, violence and violent images, disordered eating/weight etc. ***add a trigger warning or you will be asked to resubmit it.***

Autism Late Diagnosis Support and Education:

/The Autistic Cooperative:

private group > 7,800 members

“The group was originally set up as a support group for parents and Autistic people by Becky Noble. It was always a mixed group but over time the needs and priorities of late-diagnosed and self-identifying Autistic people became more paramount.

*Kieran Rose, The Autistic Advocate was asked to become lead admin, so the group came under the stewardship of a **networking and lobbying organization he founded called The Autistic Cooperative** (<https://www.facebook.com/TheAutisticCooperative/>).*

From that point this group became solely for late-diagnosed Autistic people & those who self-identify; a sister group was set up for parents and families.

(<https://www.facebook.com/groups/586219365162726/>)

The Admins in this group are nearly all from The Autistic Cooperative and, of those, all are either Professional or semi-Professional Advocates and have been doing this for a long time. A number of us work in the field of Autism as Autistic Professionals in various capacities, but every Admin gives their spare time to this group for free.

*As a warning: You may find people sometimes **using functioning labels and terms that are rightly being pushed aside as we move out of the 1940's thinking that still perpetuates the Autism narrative.** You may see Functioning labels, the use of Aspergers and such-like.*

*The reason this group, nor its admins, is **not aggressively correcting those things** is because it's an **education and support group**. We **guide discussions, let through positive and educating blogs and vlogs and articles and take a soft approach**, simply because **among the newly and later diagnosed, many people have not been immersed in this understanding.***

*Some of us have had the privilege of 20 years or more to wrap their heads around this; Some reach these conclusions quicker than others. **We won't allow anyone to be rushed or forced.** It's important that we all come to understand the narrative that harms us. We owe it to each other as much ourselves. To think solely of ourselves is selfishness. We have to reach these conclusions in our own time and in the meantime have some patience with others.*

*We rely on members who understand the issues we face and the narrative we live under to help **gently support others into more accepting and inclusive ways of thinking.***

If you come across any Martyrs, Behavioural therapy supporters, Cureists and so on please let us know so that they can be ejected as quickly as possible.”

Aspergers Support Group for Women:

private group > 700 members

*“The first goal of the group is to offer a **safe space for women without NT judgment for asking advice, sharing experiences, or connecting socially.**
Ableism and misogyny are not welcome here.”*