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Chloe Farahar

Autistic identity, culture, community, and space for well-being

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A tale of two "autisms"

As with much human phenomena, multiple narratives can be used to attempt to understand the phenomenon termed "autism". At present, there are largely two opposing narratives: the pathological and paradigmatic narrative that constructs "autism" as a medical neurodevelopmental "disorder"; and the neurodiversity paradigm, constructing Autistic experience as a natural variation within the human species, enacted upon by the societal powers and ideological notions of "normal", in need of acceptance and societal accommodation and support (Bertilsdotter Rosqvist, et al., 2020; Farahar and Bishopp-Ford, 2020; Kapp, 2019; Walker, 2014; Jack, 2011). While I begin by comparing these two narratives of autism and Autistic experience, I wish to assert how Autistic identity, culture, community, and space components are part of a non-linear process. For example, some Autistic individuals enter Autistic spaces and then build their identity as an Autistic person, finding, through their identity development, the community and culture; while others have a keen sense of Autistic identity and thus seek out or create Autistic spaces.

It is important to note that I am not the first to discuss the importance of understanding Autistic experience within and from a perspective of identity, culture, community, and/or space, and there are some thorough and well-reasoned discussions on these dimensions (cf. Botha, 2020; Chapman, 2020; Cooper et al., 2020; Belek, 2019; Kapp, 2019; Fletcher-Watson and May, 2018; Gokh et al., 2018; Cooper et al., 2017; Anderson, 2013; Owren, 2013; Straus, 2013; Sinclair, 2010; Davidson, 2008; Dekker, 1999). Ultimately, my purpose in writing this chapter is to highlight the importance of Autistic identity, culture, community, and space for Autistic well-being, beginning with the harm the "culture of autism" causes members of our community.

The "culture of autism"

Autism as an abstract concept is defined as a persistent impairment in reciprocal social communication and interaction; restricted and repetitive patterns of behaviour, interests, or activities; all of which may relate to hyper-reactivity (avoidance) or hypo-reactivity (sense seeking) to sensory input – with or without accompanying intellectual disability and/or language impairment (World Health Organization, 2019; American Psychiatric Association, 2013). This clinical, abstract way of defining autism is used within the "culture of autism" and applied to human beings, where "people with autism" are disordered, faulty, "normal" people with deficits.

One might wonder how an Autistic culture and collective identity can exist if it is not based on shared medical symptoms or what can connect us if not symptomatology. Much like other minority groups with shared social, sensorial, and political experiences of the world (e.g. LGBTQIA+; Black; Indigenous; Persons of Colour; women), the Autistic community is built on shared Autistic experiences – both positive and negative. While the non-autistic derived medical symptomatology comprises a list of attributes that reflect an Autistic in distress (largely autism "symptoms" can be understood as trauma responses), there is fundamentally more to being Autistic than what the diagnostic manuals reduce us to.

Given that the dominant, existing pathology narrative of autism is predicated solely on the interactional struggles of the "person with autism", it is then no surprise that the culture of autism (and its narrative) harms us collectively and individually (as internalised self-stigma and negative self-worth) (Botha and Frost, 2020). To subvert this negative and dehumanising narrative, many Autistic people come to distance themselves from autism and other "people with autism". This distancing is done to protect themselves by rejecting an autism that is based solely or largely on shared deficits and symptoms, as there is little positive self-esteem or self-worth derived from connecting with others based on such inherently negative experiences and narrative (Cooper, Cooper, Russell and Smith, 2020). This distancing leaves many "people with autism" in purgatory: neither belonging to a non-autistic community, identity, or space (even when they [we] try, when they [we] mask), or Autistic spaces; they are isolated from belonging.

However, the medicalised, pathologising narrative of autism is not the only (or even most persuasive) narrative about Autistic experience.

Autistic culture

We have seen a (laborious, slow, and ongoing) move away from autism as a medical pathology to a social construction, whereby Autistic people "comprise a definable minority group" (Straus, 2013, p. 466), and group cohesion is based on shared experiences, not medical "symptoms". Autistic culture works from a shared understanding of the neurodiversity paradigm, where Autistic experience is a natural variation within the human species, enacted upon by social power relations and ideological notions of "normal" (Farahar and Bishopp-Ford, 2020; Walker, 2014); where Autistic experience needs acceptance and societal accommodation and support, not intervention or "cure". This move from the abstract "autism" to diverse and identified Autistic people is shaped by and perpetuates shared culture and community, where Autistic people (not non-autistic researchers or clinicians) define what Autistic experience is and convey what being Autistic means. This shared, depathologised meaning is in turn transmitted to other Autistic people via "the culture we produce [such as our writing, art, and music]"

(Straus, 2013, p. 466). From an Autistic perspective therefore, autism can be defined as:

> [A] neurodevelopmental difference, where Autistic brains work differently to non-autistic people. There are as many different brains and ways of experiencing the world as there are different bodies. There is a variety of Autistic people, just as there is a variety of non-autistic people, but all Autistic people share some similarities. These similarities include:
>
> - differences in experience of the sensory world,
> - differences in communication,
> - differences in thinking, socialising and moving.
>
> Some Autistic people need support with day-to-day living, and within this perspective there is no one way to be Autistic.
>
> (Autistic Self Advocacy Network, 2020)

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Culture itself can be defined as "[t]he ideas, customs, and social behaviour of a particular people or society" (Oxford University Press, 2020). When you learn about Autistic community and connection, it is not difficult to see that many Autistic people embody this definition of culture: sharing ideas about Autistic experience (as understood within the neurodiversity paradigm[1]); sharing customs and social behaviour (e.g. modes of greeting). As a culture we have our own beliefs, values, and practices, our own language (Davidson, 2008) and understanding of communication. This communication is at odds with non-autistic people, and under the pathological paradigm is argued to be evidence of deficit and disorder. However, in Autistic culture it is understood and shared as valid, understandable, and valued.

In groups of two or more Autistic people this shared language and communication can be straightforward and honest; it can be orally verbal, or gestural, and not understood outside of Autistic interaction (see the double empathy problem; Milton, 2012). For example, known in the culture of autism as "self-stimulatory" behaviour, stimming is a language and communication in and of itself (Kapp et al., 2019; Kim and Bottema-Beutel, 2019; Bascom, 2012). I can discern from the slightest fingernail flicking and rubbing that a fellow Autistic is anxious; from the near imperceptible rocking of an Autistic friend that they are on the verge of meltdown; from the neutral "Autie" face, that they are deep in thought. We talk in spoons[2] (units of energy; Miserandino, 2003), specialisation[3] info-dumps, and echolalia.[4]

Attempts to frame and understand Autistic experience from an anthropological perspective have proven useful. Belek (2019) and Gokh, Mineev, and Viktoruk

(2018), for instance, help us see that Autistic experience is not the same as autism in the abstract. Gokh, Mineev, and Viktoruk (2018, p. 1954) argue that Autistic people have an Autistic "community consciousness", one derived from a cultural identity as we as a collective share:

1. Cognitive (mental), communicational, linguistic, and symbolic cohesion
2. [A] feeling of universal oneness of [an] autistic population
3. Group conscience (social awareness, social responsibility)
4. [An] awareness of deep commonality of long-term interests; unity of destiny
5. [A] sense of joint purpose, [a] mindset [for] transformation, [and] personal growth

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With research and discussion of Autistic experience from anthropological, ethnographic, sociological, and social psychological perspectives, we are seeing growing evidence for a more three-dimensional understanding of autism, where Autistic people are being taken off "the spectrum" and placed more firmly in a three dimensions[5] Autistic space (Farahar and Foster, 2019). Understanding

Autistic people outside of our objectification as “people with autism” may help to humanise our suffering and better focus research and clinical interest on our well-being issues, moving away from focusing on autism in the abstract.

Autistic well-being

Tragically, the Autistic community is subjected to a great deal of trauma due to living in a sensory environment not suited to us, and a society not accepting of us (Crane et al., 2018; Kupferstein, 2018). Consequently, our community experiences high rates of trauma responses (Griffiths et al., 2019). For example, we experience greater levels of anxiety and depression (and other mental health issues, compared to non-autistic, neurotypical controls) due to our “navigating a neurotypical world” (Crane et al., 2018, p. 8). Our community also contends with bullying (Fisher and Taylor, 2016; Cappadocia et al., 2012); loneliness (Lounds Taylor et al., 2017; Orsmond et al., 2013); and abusive and violent victimisation (Griffiths, et al., 2019). We die on average 16 years earlier than our non-autistic, predominant neurotype counterparts, with a mortality rate of age 54 in our community. The leading cause of death for those in our community (without an intellectual/learning disability) is suicide, with an average age at death of 58 years (compare this with the general population mortality rate for the UK of 82 years for women, 79 years for men; Barton and Hawkins, 2018; Hirvikoski et al., 2016). Detrimentally, most intervention focuses on attempting to make us appear non-autistic, even in the face of evidence demonstrating that attempts to do so are correlated with post-traumatic stress responses (Kupferstein, 2018). It is only more recently that we are starting to see a focus on our personal well-being, and how this might be improved with connection to other Autistic people.

The importance of Autistic culture (whether non-autistic or Autistic people alike refuse to relinquish the pathological understanding of autism) comes from its protective properties. What I have seen in the work I do supporting Autistic students, is that those who come to us embodying and living the "culture of autism" narrative (they have deficits; they are a "person with autism spectrum disorder") experience loneliness, isolation, and a negative sense of self. This is what the pathological narrative *gives* Autistic people – hopelessness, isolation, and loneliness. Autistic culture, on the other hand, has afforded these same people a distinct perspective, one where they can connect with others based on similarity, positive self-worth, hope. Whether you believe that to be Autistic is to *be* a pathology or to *have* a disorder, becomes moot in the face of growing evidence that Autistic identity, culture, community, and space improves well-being (Cooper et al., 2020; Cooper et al., 2017; Spandler and Anderson, 2015; Griffin and Pollak, 2009[6]). It should be enough to relinquish the culture of autism when you learn it harms, and that an alternative narrative improves well-being. And so, I argue, it is fundamental for our population's well-being to foster a positive Autistic identity, and to do this we need to find other Autistic people (see Table 19.1 for the key components of the "culture of autism" versus Autistic culture).

Fostering a positive Autistic identity: the social cure

By virtue of diagnosis, I *belong* to the stigmatised category of “people with autism”. Belonging to this category of people means I and others are confronted with stigmatising stereotypes (unsocial, quiet, emotionless; Treweek et al., 2019); prejudicial attitudes (benevolence, anxiety, fear); and discriminatory behaviours (avoided, ignored, not considered for jobs or promotions; Bunt et al., 2020). Not only are we targets of stigma, but we also internalise these attitudes. Bombarded with public stigma, it is easy to see how “people with autism” internalise these attitudes as self-stigma, a phenomenon known to negatively impact self-esteem, efficacy, and well-being (Corrigan, Larson, and Ruesch, 2009). With this pathologising narrative, it is also easy to see why many of us struggle to foster a positive identity.

Fostering a positive identity is further impeded by non-autistic people who will state that we ought not identify as Autistic, that we ought to separate ourselves from the fundamental thing that differentiates and alienates us within current society: our Autistic experience. We are accused of creating an identity based on something that is characterised as an alleged pathology, where it cannot be an identity by virtue of its pathologisation. However, quite simply, those who insist on the pathologising narrative and label of “person with autism” have thrust upon us an “autism” identity. Calling me a “person with autism” *is* an identity, just one I did not have any say in. There are two key ways of avoiding the negative impact of belonging to a stigmatised group. The first is to distance oneself from the stigmatised group – "I am nothing like those people with autism". The second is to *strongly identify* with the social group.

When belonging to a stigmatised group – i.e. "people with autism" – we can employ several strategies to manage the stigma directed at the group overall, which include individualistic and collectivistic strategies (Perry et al., 2020; Jetten et al., 2012). At the individualistic level, we can attempt to remove ourselves from the group – figuratively or literally – to dissociate from the group "people with autism", to protect our self-esteem, self-worth, and well-being. This, I argue, can lead Autistic people to become isolated. Even when we attempt to "pass" as non-autistic, to connect with social identities that are non-autistic, we never get it quite right. Our natural and inherent "autisticy" (ways of being and interacting in the world, Gates, 2019) is still called out by others, and it still separates us from non-autistic, predominant neurotype others. And so, by deciding to dissociate from the Autistic identity and group, we separate ourselves from the protective properties of the collective, but do not necessarily protect ourselves from future discrimination.

Separating oneself from the stigmatised category of "people with autism" – although a valid means of attempting to maintain positive self-identity – sadly means that many Autistic people do not have the connection to those who could understand and accept them, and who could, importantly, offer collective support. Distancing from Autistic people can mean heavy masking of one's authentic self – to appear as indistinguishable from non-autistic peers as possible. This masking method is known to cause Autistic people harm (erroneously referred to as camouflaging in the literature, but more accurately as masking in the community; Pearson and Rose, 2020; Cage and Troxell-Whitman, 2019). It also means that the protective properties of belonging, and both material and social resources, cannot be accessed, that we run the risk of poor well-being through living inauthentic and overwhelming lives, alone. The opposite of distancing from a stigmatised group – strongly identifying with the social identity of *Autistic person* – brings with it many benefits, and helps individuals protect against the effects of stigma. Simplistically, this can be seen as strength in numbers – a collectivistic "social cure" (Jetten, Haslam, and Alexander, 2012).

At the collectivistic level we can derive resources, symbolic (kind words or feelings of connection) and material (offers of practical support), from fellow community members. When we take pride in not only *belonging* to a stigmatised group but strongly *identifying* with the group, we can collectively combat the discrimination directed at us, together. Importantly, as noted by Jetten, Haslam, and Alexander (2012) in their discussion on the social cure capabilities of social identity, we may be more likely to adopt the collectivistic strategy when we can see our collective ability to alter the intergroup relationship between our stigmatised minority group and that of the powerful majority. As Jetten, Haslam, and Alexander (2012) suggest, for those who adopt the individualistic strategy – i.e. to dissociate from the Autistic community – they may not be able to see the possibility that as a group we can alter the power dynamics that are currently not in our favour. However, when embraced, this "social cure" can improve well-being.

Having a positive Autistic identity can reduce indices of anxiety and depression and does so by increasing collective self-esteem (self-esteem for the Autistic group overall), and consequently increases personal self-esteem (Cooper et al., 2020; Cooper et al., 2017). This is one area of well-being evidenced as improved by strong social identification with the collective *Autistic*. Given the "illegitimate, pervasive, [and] difficult to avoid" (Branscombe, Fernández, Gómez, and Cronin, in Jetten, Haslam, and Alexander, 2012, p. 118) discrimination Autistic people face in every aspect of daily life (education, employment, medical services, and so on), it is almost inevitable that we should come together as a community to fight for social change of our subordinate position. If as individuals we strongly identify with the Autistic social identity then it, too, is inevitable that we would shape, perpetuate, and maintain an Autistic culture, one connected via an Autistic community.

Creating Autistic communities and space: healing, refuge, and alternatives to diagnosis

The way in which many Autistic advocates and community members challenge the dominant medical narrative of “autism” is, much like the Voice Hearing community, which was pathologised as having “psychosis” or “schizophrenia” (Hart, 2020), by finding others who share similar experiences of the world as Autistic people; within spaces built for Autistic experience of the world; maintained and respected through shared culture and community, which rejects our objectification as “people with autism” for a fuller, reclaimed humanised Autistic identity. It is within these Autistic communities and spaces that we as stigmatised and traumatised individuals can take refuge and begin to heal. We are seeing evidence that what is important for Autistic well-being is Autistic friendship and community, with research starting to focus on peer support (Crane et al., 2018) and understanding the Autistic self:

> I never realised everybody felt as happy as I do when I am around Autistic people.
>
> (Crompton et al., 2019, p. 1438)

Autistic communities and space: healing and refuge

There are numerous Autistic spaces throughout the UK – on and offline – that offer healing for harms done to Autistic people by a rigid society currently not embracing difference. These spaces offer refuge from the stereotyping and prejudicial narrative, and the discriminatory behaviour many of us experience daily outside of these spaces. Community spaces such as Annette Foster's and my University of Kent Autistics social group, spaces such as Autism Inclusive Meets (autisticinclusivemeets.org), events such as the Playing A/Part Inside-out Conference (playingapartautisticgirls.org/inside-out-conference-2019), Autscape (Milton and Sims, 2016), Autcraft (an online Minecraft server; Ringland, 2019), and Scottish Women's Autism Network's Under our Wing mentoring (Stewart, n.d.) are examples of such refuges sheltering Autistic people of varying support needs, allowing attendees to exist in a space where different ways of being, thinking, and behaviour are not only accepted but encouraged and embraced. In these spaces you can see the non-pathologising narrative start to break through and break down internalised ableism, stigma, and invalidation trauma (Gates, 2019); where real friendships can be encouraged and fostered (I met Annette in such a space).

In these spaces, positive Autistic identities begin to form by learning about and becoming a part of Autistic culture, where these small pockets of community protect against the pathologising narratives that exist outside the walls. Where "[t]he walls of the community work to keep community members safe" (Ringland, 2019, p. 132). In these spaces, Autistic people can make their Autistic noises and gestures; share in their stims – placing objects on their head and saying "hat",[7] encouraged to do so because it is a behaviour that is understood; inhabit the space, never having to say a word (due to experiencing situational mutism; social anxiety), but still a vital part of the group; hide behind a curtain throughout a social session because of overwhelm, but wanting to be part of the community – energised by this form of participation, still seen as *participating* in the space in this way.[8]

Autistic communities and spaces are healing refuges because they show Autistic people a different way to inhabit space, one based on positive Autistic identity and Autistic cultural norms. These spaces allow members to be authentic (for many for the first time), *and to not only be accepted but embraced as such*. Perhaps one day these community spaces will be less “ghettoised”,[9] when we will not have to protect ourselves so readily from non-autistic spaces. But until that time comes, these spaces are vital to our well-being, social identity, and authenticity. These communities and spaces may also come to be understood as more appropriate contexts with which people come to discover they are Autistic.

Autistic communities and space: an alternative to diagnosis

While I was a PhD student (investigating the reduction of mental health stigma via the neurodiversity narrative), I discovered my Autistic identity.[10] I fully immersed myself in Autistic culture and community and created the Autistic spaces our community desperately needs. With this space (a social space for

Autistic university students, of varying support needs, from typical social difficulties creating and maintaining friendships with non-autistic people, to those who are situationally mute and/or minimally orally verbal) I went on to develop a structured support programme for more vulnerable Autistic students, co-developed and facilitated with fellow Autistic, colleague, and friend, Annette (of Super Autie Grrl, and later, Super Autie Gang, fame). The purpose of this structured support programme – So, You're Autistic? (SYA?) – was and is to offer eight small-group sessions to vulnerable Autistic students.

The practicalities and purposes of this structured programme (which among its formal purposes) seek to help deconstruct the harmful internalised pathologisation of typical Autistic experience of its attendees; foster a more positive self-identity; support attendees to find coping mechanisms for feelings and behaviours that distress; as well as foster a sense of community. The latter is something that many attendees have never experienced, alienated as they have been from society and one another by the pathology paradigm. This early alienating effect of being a "person with autism" is demonstrated by one SYA? attendee, who replied with the following when asked "How did you feel about the idea of being Autistic prior to attending SYA? How do you currently feel about being Autistic?":

> [before] It stops me from ever being normal or fitting in and stops me from doing things I want to do, it's a weakness and an excuse to not be able to do things.
>
> [currently] It's okay to be different, there are other people who will understand me and it's okay to need help with things or need to do things differently, I have my own strengths that other people don't.
>
> I thought I could be Autistic on my own and no one had to really know and now I want to tell people and find more people who will relate to the things I do.
>
> (SYA? attendee, 23-year-old cis female, Sophie, June 2020)[11]

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Several of our programme attendees come to us with low self-esteem and poor well-being, having internalised negative perceptions of themselves – pathologised perceptions. It is Annette's and my role to help them see that they are not alone, and to help start to reframe their understanding of autism in the hopes they can start to heal from the internalised stigma. When attendees start to see one another's challenges *and* strengths, they reframe negatives into positives, for example "I talk too much about my special interest" becomes "I am knowledgeable about my specialisations and can share them with other Autistic people”. To help solidify this reframing, attendee’s appliqué positive words or phrases on to clothing, pillowcases, or make banners – something to remind them when they are struggling that there are also strengths to being Autistic.

Figures 19.1–19.4 show appliqués made by SYA? attendees. This is an activity we carry out during the 8-week programme with the aim of helping attendees reframe the negative narrative they have of themselves.[12]

Currently, the process of Autistic discovery is via pathologisation of Autistic experience and expression. For instance, it is rarely the case that an Autistic person – child or adult – is flagged for assessment when they are happy. Parents, educators, general practitioners, and paediatricians push for diagnosis of Autistic children because they are struggling, in distress, and often at their lowest point. Late-discovered Autistic people are diagnosed under similar circumstances: they may have experienced many mental well-being issues growing up and into their adulthood and reach a breaking point where they seek diagnosis, or assessment is recommended by employers, family, and friends, or through self-realisation. This is all based on struggling and distress. A case in point would be parents who request assessment for their child because they know they are Autistic, but the school or general practitioner state that their child is not struggling, or not struggling enough. All these situations set children and adults up to link being

Autistic – the diagnosis – with distress, in turn painting being Autistic in a negative and stigmatising light. As already discussed, this pathologisation of difference, from pre-diagnosis through diagnosis, and post-diagnosis, is internalised, isolating, and damages well-being. There is another way.

I argue that Autistic discovery (not diagnosis) ought to be discovered holistically, kindly, and safely, in similar ways to discovering other aspects of one's identity and experience of the world, such as one's gender, sexuality, personality, and so on. A depathologised model would mean we discover we are Autistic when we are in a good place, when our well-being is not poor. This discovery of one's Autistic-ness would be based on positive sensory differences and experiences, not negative ones. This would alter perceptions of Autistic experience for the Autistic person, as well as for society at large. I hear frequently from Autistic children and adults who blame their autism for everything negative in their life, not understanding that when they are doing okay, even thriving, it is because their environment – social, emotional, sensorial – is optimal. We are Autistic in these optimal moments too, and autism should be "blamed" for these experiences and periods in our lives as much as when we struggle and suffer (although our suffering is the result of the interaction between our Autistic needs and the environment not being homeostatic).

I propose that the use of Autistic-led programmes, such as my and Annette's So, You're Autistic? programme, are more effective for discovering ones Autistic-ness as a teen or adult compared to current infantilised and gendered medical diagnosis processes. Within our SYA? programme for instance, all Autistic people – those struggling and in distress, and those who are thriving – are equally able to discover their Autistic identity – the culture, community, and spaces that can educate and support them to understand themselves and other Autistic people. This is what Autistic discovery should be: a journey with similar others.

In summary

In this chapter I have discussed and compared the "culture of autism" with the narrative of Autistic culture, illustrating the damage that the former has on Autistic well-being, devoid as it is of positivity, hope, or connectedness. I have highlighted some of the well-being issues we experience, such as the higher rates of trauma and trauma responses the (my) Autistic community faces: the greater rates of depression, anxiety, suicidality, and mortality compared to many non-autistic populations. I have described how fostering an Autistic identity can act as a "social cure", one that affords Autistic people both symbolic and material support from fellow community members. I demonstrated how the material and symbolic supports an Autistic identity confer can come in the form of Autistic spaces that offer refuge and healing from prejudice and discrimination.

Evidence exists to show that public and internalised, self-stigma can negatively affect well-being (e.g. Botha and Frost, 2020; Link et al., 2017). It is not being Autistic – the differences in experience of the sensory, social, and emotional world – that negatively impacts us. According to the central tenet of the social model of disability, it is the way the environment and those in society treat disabled people that causes us our greatest struggles (Chown et al., 2017). To combat this, there needs to be systemic change. Until then, "people with autism" need support to find and foster a positive Autistic identity to combat the negative effects of the pathologisation of Autistic experience. To foster this positive Autistic identity, we need to find and immerse ourselves in Autistic spaces – spaces where we can learn about our culture and build our community.

As outlined, it is also still my hope that my proposition for an alternative to diagnosis is embraced, where I argue that Autistic-led programmes are better placed to help Autistic people discover their Autistic-ness. It is my fervent wish that one day individuals can discover their Autistic identity in the same way that LGBTQIA+ community individuals come to realise who they are – through seeking answers to feeling different via the community, as opposed to pathologising diagnostic assessment.

Ultimately, I have argued that to improve Autistic well-being, Autistic individuals need a positive social identity (connecting with an Autistic identity); to embrace

Autistic culture and its positive narrative (avoiding the "culture of autism" which pathologises Autistic experience, which is in turn internalised); to foster and immerse oneself in an Autistic community; and to create and search for Autistic spaces for healing, refuge, and discovery (as an alternative to diagnosis) of one's Autistic identity. In these ways the Autistic collective can combat the stigma and oppression our community faces, *together*.

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Figure 19.1 "Embrace your weird"

Figure 19.2 "The Great Autismo"

Figure 19.3 “Awesome”

Figure 19.4 “Autistic good”

Table 19.1 The key components of the “culture of autism” versus Autistic culture

"Culture of autism"	**Autistic culture**
• Person with the disorder "autism" • Disease/disorder/illness • Mental illness • Problem/issue • Challenging • Violent • Deficit/impairment • Low-functioning • High-functioning • Severe/mild autism • Pathological • Symptoms • On the spectrum • Cure/treatment • Intervention/strategies • Risk of autism • Special interests • Awareness • Researched on	• Neurodiversity paradigm – difference, social models • Focus on strengths, support for challenges • Language and customs – Autistic identification • Stimming language and activities • Community • Spaces and environments • Positive symbols • Fluctuating support needs • Specialisations • Shared commonalities (no spectrum, but existing in three-dimensional space) • Understanding and acceptance • Research with, for, and by Autistic people

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[1] Not to be confused with the neurodiversity movement (Walker, 2014).

[2] Spoon theory refers to the disability metaphor defined by Christine Miserandino (2003) who has Lupus. To explain the limited energy a disabled person has compared to a non-disabled person Christine had to hand cutlery – spoons – to demonstrate to a non-disabled friend how much energy she expends in a day, which is considerably more than a non-disabled person. Autistic people use spoon theory, and it is not unheard of for us to say "Sorry, I don't have the spoons today" when asked to do something we do not have the energy for.

[3] Specialisations, not "special interests".

[4] Echolalia is the repetition or echoing of sounds or words.

[5] Dimensions, not dimensional, as the three dimensions within the Farahar and Foster Autistic space exist along three axes (internal, external, time).

[6] Griffin and Pollak (2009) demonstrate in a small qualitative study that the medical narrative of neurodivergent students correlated with poor self-esteem, finding the opposite in neurodivergent students who embraced the neurodiversity narrative. This is something Annette and I have witnessed and seen improve with students who come to both our University of Kent Autistics group, and So, You're Autistic? support programme.

[7] A reference, with permission, to a student who attends my University of Kent Autistics group.

[8] A reference, with permission, to a second student, Jessica, who attends my University of Kent Autistics group.

[9] A reference to a non-autistic researcher's perspective of these spaces.

[10] And was formally diagnosed early 2017.

[11] Direct quotes used with permission. Taken from anonymous SYA? programme feedback. Credited, with permission, to Sophie.

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[12] Photographs of example SYA? attendee appliqués used with permission. Credited, with permission, to Madie, Harvey Bolton, Ben, and Leo Burns.