

## **Title: Critical autism studies: exploring epistemic dialogues and intersections, challenging dominant understandings of autism**

In this paper we explore how our cultural contexts give rise to different kinds of knowledges of autism and examine how they are articulated, gain currency, and form the basis for policy, practice and political movements. We outline key tensions for the development of critical autism studies as an international, critical abilities approach. Our aim is not to offer a cross-cultural account of autism or to assume a coherence or universality of 'autism' as a singular diagnostic category/reality. Rather, we map the ways in which what is experienced and understood as autism, plays out in different cultural contexts, drawing on the notion of 'epistemic communities' to explore shifts in knowledge about autism, including concepts such as 'neurodiversity', and how these travel through cultural spaces. The paper explores two key epistemic tensions; the dominance of 'neuro culture' and dominant constructions of personhood and what it means to be human.

### **Points of interest**

- Autism is often seen as a medical problem, which means that scientists try to understand it mainly in terms of how people's brains work
- This paper argues that this way of understanding autism can be a difficult prove and is not the only way of thinking and researching autism
- A different way of understanding autism that values the abilities of people with autism is discussed in the paper.
- We show how autism is understood differently in different parts of the world
- We argue that ways of supporting people with autism vary across the world

## Introduction: placing critical autism studies

In this paper we outline the developing field of critical autism studies. We do so by drawing on our five different national contexts to offer points of similarity and difference in ways in which autism is understood, acted upon and experienced. The paper has emerged from discussions we have had about how the various locations in which we live and work (Australia, Brazil, Canada, Sweden and the UK) understand and conceptualise autism. It is clear from our various positions that public discourse surrounding autism has had increased visibility over the past decade. However, this has been articulated differently across the contexts in which we work; for example in Brazil there has been a focus on psychoanalysis and psychiatry, whereas in Sweden the focus has been on autism as part of a broader group of “neuropsychiatric disabilities” (foremost including ADHD, ADD, autism and Tourette syndrome), independent living and employability of people with autism.

We share a concern with dominant constructions of autism as they are largely (but not exclusively) located within a neurobiological frame, and seek to challenge dominant understandings of autism as a neurological deficit, instead focusing on autism as an identity that is materially and discursively produced within specific sociocultural contexts. We explore different kinds of knowledges of autism as they are articulated, gain currency, and form the basis for policy, practice and political movements.

The paper begins with an introduction to critical autism studies and the core theoretical elements formulating this position. The concepts of intercontextual knowledge and epistemic communities, both central to our theorising of autism through different cultural locations, are introduced. Rather than assume a cross-cultural analysis of autism we draw on an analytic frame of epistemic communities through which to articulate and develop the field. Epistemic

communities allow us to theorise the production of autism within particular cultural contexts. The concept of ‘intercontextual’ enables us to consider how ideas about autism travel between contexts and between groups with different agendas and engagements with the production of knowledge about autism. We examine two key epistemic tensions in developing a critical autism studies agenda: neuro culture and being human. The paper ends with our thoughts on a future research agenda for critical autism studies.

### Critical autism studies

The term “critical autism studies” was coined in 2010 by Davidson and Orsini following a workshop in Canada that culminated in their co-edited collection, *Worlds of Autism: Across the spectrum of neurological difference* (2013). At the time, the exact contours of this emerging field were far from established, but they did identify at least three elements of an approach, on which we seek to build here.

1. Careful attention to how power relations shape the field of autism
2. Concern to advance new, enabling narratives of autism that challenge the predominant (deficit-focused and degrading) constructions that influence public opinion, policy and popular culture; and
3. Commitment to develop new analytical frameworks using inclusive and non-reductive methodological and theoretical approaches to study the nature *and* culture of autism. The interdisciplinary (particularly social sciences and humanities) research required demands sensitivity to the kaleidoscopic complexity of this highly individualised, relational (dis)order. (Davidson and Orsini, 2013, p 12)

Critical autism studies are therefore informed by and remain complementary to critical disability studies in the core elements of research focus, theoretical frame and politics (see for

example, Goodley, 2013; Pothier & Devlin, 2006; Meekosha & Shuttlework, 2009). However, the focus of research is placed on issues specific to autism rather than on the broader construct of disability. While complementary to critical disability studies, critical autism studies also troubles the common sense understanding of (dis)ability through interrogation of the construction of autism as a spectrum of difference configured as social and cognitive impairments, which may sit uneasily within a (dis)ability framework. Critical autism studies is interested in the neurologisation of autism in academic, professional and lay discourse, which positions both individuals with autism and, depending on context, non-autistic others (referred to as either ‘neurotypicals’ (NTs) or non-autistics). The assumption of a non-autistic ‘norm’ is, in conventional understandings, unquestioned and naturalised. Hence the terminology used within our work is purposefully to signal a rejection of the more pathologising reference to ‘normal’ or ‘typical’ (Davis, 1995) and questions the assumption of a non-autistic world view as our main point of reference.

Critical autism scholars are not, however, required to adhere to a firm, unmoveable set of criteria in delineating whether they are authentically critical, of course. The elements identified by Davidson and Orsini are intended to open new lines of inquiry, not foreclose the potential for critical scholarship in the autism field, especially research that bring advocates and academics from social sciences and humanities into productive tension and dialogue with dominant neurobiological approaches to understanding autism. One obvious challenge for critical autism researchers is to take seriously commitments to scholarly inquiry that avoids reproducing the hierarchical relations that govern research with so-called “vulnerable” populations. This means making a commitment to the meaningful involvement in research of people with autism themselves, in much the same way that research in many areas of identity politics and health

issues (such as feminist, LGBTQ and HIV/AIDS) is guided by principles of meaningful involvement. It is clear that within critical approaches to autism there is no sustainable dichotomy between non-autistic academics who study autism and autistic scholars/academics. At the same time, if we are to take seriously the call to critical inquiry, we need to ask the difficult questions of knowledge produced by and for people with autism. It is clear that people with autism do not speak with one voice. Anything less would be fundamentally insulting and harmful to people with autism themselves, and the myriad knowledge and experience they mobilise in the field of autism.

Outside of the academy, autistic self-advocacy movements in many countries have developed to challenge autism advocacy that is often led by individuals who are not on the autism spectrum, or who are more interested in curing autism rather than assisting individuals who need social services or welfare supports. The role and purpose of these self-advocacy organisations varies across cultural contexts, and we should be clear that the continuum of advocacy varies from loosely organised self-advocates operating almost as individual actors to more formalised organisations such as the Autistic Self Advocacy Network in the US led by Ari Ne'eman and the National Autistic Society in the UK. In comparison to self-advocacy organisations in the US, Canada and the UK, Satedi, the French autistic persons' organisation has eschewed radical disability organising, stressing the role of education and information activities for people with autism and remaining under the influence of parent associations, as opposed to people with autism themselves (Chamak, 2008; see also Chamak, 2014; and Chamak & Bonniau, 2013). Similar to the French contexts, in Brazil, organisations formed by civil society provide services and information to parents about autism and intellectual disabilities in general. These organisations range from philanthropic institutions to parent advocacy and

support groups, they offer a range of services, from information and support for parents to medical and educational services (Rios and Costa 2015). In Sweden there is an established self-advocacy movement that has worked both separately from and in close cooperation with parent dominated associations as well as with allies among health professionals (Bertilsson Rosqvist et al, 2015). In Canada, there is a mix of organisational types, as well, with organisations that are off-shoots of U.S.-based groups such as mainstream organisation Autism Speaks, as well as other smaller organisations focused on framing autism care as a universal right under Canada's system of health insurance (Orsini & Smith, 2010).

#### Intercontextual knowledges of autism, cognitive normality and a critical abilities perspective

We take as a starting point valuing the skills and agency of people with autism and work to demonstrate the ways in which dominant assumptions do not fully account for the skills, abilities and identities of people with autism. The implications of moving away from a deficit-focused understanding of autism to a critical abilities framework is twofold. Firstly, it helps to reframe the autistic subject in ways that appreciate the complex personhood of individuals on the spectrum. Secondly, it invites critical re-formulations of normative assumptions of 'ability', such as taken-for-granted assumptions of formal and informal/social competencies required for employability and the world of work. As critical autism researchers we question the received wisdom about what constitutes knowledge, as well as simplistic and harmful dichotomies, including that between fact and value. Drawing on Goodley (2014) we are considering autism through the split term dis/ability. He stresses that disablism and ableism and disability and ability must be understood simultaneously in relation to each other. Goodley writes "The slashed and split term denotes the complex ways in which opposites bleed into one another. (...) Dis/ability

studies keep disableism and ableism, disability and ability in play with one another, to explore their co-construction and reliance upon one another.” (Goodley, 2014, xiii)

In contrast to the prevailing deficit construction of autism, which is individualising and pathologising, a critical abilities framework not only respects the complex personhood of autistic individuals but also reveals how the construction of autistic identities holds important insights for how to rethink, and extend, ideas associated with cognitive ‘normalcy’ (or ‘ability’) and difference.

Occupying a variety of different theoretical, conceptual and political positions as a group, we are interested in creations of ‘autism’ as something happening *somewhere*: in the individual’s narratives/stories of themselves, cultural expressions such as art and literature, legal texts, scientific texts, health manuals, autobiographies, newspapers, magazines, political activism and interviews, etc. All of these situate autism in particular ways in different cultural contexts, but which sometimes pan and move between them. Hence in this paper we use an *intercontextual* approach to examine how the concept of ‘autism’ is articulated in different contexts and how particular discourses move across contexts and gain power and legitimacy. By intercontextual, we do not seek to offer, or assume, a ‘cross cultural’ perspective on autism; neither do we offer, or suggest that autism is a universal diagnostic/experiential truth understood similarly across cultural contexts. Rather, our various vantage points provide different cultural contexts within which to examine the construction of ‘autism’ as something that is discursively produced with material consequences (Hacking, 2002).

### Exploring epistemic communities of knowledge about autism

Our various vantage points offer points of similarity and contrast between different approaches to issues such as understanding autism in relation to dis/ability (Deshong, 2012;

Goodley, 2014; Goodley et al, 2014) (and the inclusion, or not, of autism within this complex), differences in support for citizens (i.e. within a welfare state or other forms of provision), as well as including perspectives from both the Southern and Northern hemispheres. It is clear that the academic/scientific production of knowledge about autism is firmly located within particular geographical contexts, which give rise to particular understandings of autism that have become treated as universal ‘facts’. In a recent review of the production of knowledge about autism (Curran, 2014) it was found that the majority of research has been published by academics in the USA; however the UK, Canada and Sweden are also significant producers of knowledge. It was evident in the review that the UK is increasingly producing research about autism, whereas production of published research from the global South was found to be largely absent.

We draw on the concept of ‘epistemic communities’ to argue that discourses about autism in media, policy, advocate and research communities are produced, drawn on and travel between different sociocultural spaces. The concept is developed from Whelan’s work (2007) which examined the ways in which women with endometriosis form collective identities through shared experiences of their health condition. She adapted Nelson’s (1993, cited in Whelan, 2007 p 958) conceptualisation of epistemological communities as, “a group which shares a body of knowledge and a set of standards and practices for developing and evaluating knowledge”. Epistemic communities articulate what is seen to be valid knowledge, legitimate experiences and claims to know. Nelson (1993, in Whelan, 2007) suggests that epistemological communities structure knowledge through: shared language and concepts; collective ‘public conceptual schemes’ which structure and make intelligible narratives of experience; and legitimate particular sets of theories, concepts and standards. It is evident that different perspectives on autism and cognitive normalcy arise within different cultural contexts and lead to the production

and legitimation of different knowledges. However it is also clear that particular kinds of knowledge, particularly ‘brain based’ and psychiatric explanations, have been prioritised and accorded legitimacy.

We follow the work of philosopher Ian Hacking, whose idea of ‘looping’ suggests that the classifications and categories we use to define populations transform not only the categories but also the populations so defined (Hacking, 1995, 2002). The looping effect encompasses not only scientific and diagnostic developments, but also parent and self-advocacy groups as well as general images of autism in popular movies, TV programs, personal testimonies, novels, blogs and other Internet resources. The label has undergone transformations because of changes in social contexts, developments in neuro-biological and genetic theories, as well as a constant flux of remaking through negotiations of the meaning of the label among professionals, parents and among people with autism themselves. As such the label is picked up and gains currency differently in different epistemic communities.

This is evident in the shifting diagnoses of ‘autism spectrum disorders’ through different iterations of the DSM, particularly DSM-5, which has significantly altered the diagnostic ‘reality’ of autism. The psychiatric label of autism affects the persons so labelled and/or their families, and potentially changes interpretations of their behaviour, their identities and hence the meaning of the label itself. It is evident that the removal of Asperger Syndrome from the DSM-5 and its incorporation into the single diagnosis of autism spectrum disorder, has had profound implications for many people in cultural contexts such as the UK and Sweden where the DSM exerts significant disciplinary power. This shift corresponds to the aspiration of many autistic self-advocates, such as

Jane Meyerding, who thinks that classifying people under different categories within the autism spectrum was ‘seriously misleading,’ and declared her preference for seeing herself ‘as autistic, period.’<sup>1</sup> Others regard it as a historic backlash, ‘when so many of us grew up thinking of ourselves as bad, broken and damaged, not unique and differently-wired.’ In addition, as highlighted in the online petition by the Global and Regional Asperger’s Syndrome Partnership, signed by more than 8000 individuals, many children and adults, particularly those with Asperger, will lose the diagnosis and, with it, ‘crucial supports, services and legal protections’ ([www.causes.com/actions/1593909-dsm-5-committee-dont-reduce-the-criteria-for-an-autism-spectrum-disorder-in-the-dsm-5](http://www.causes.com/actions/1593909-dsm-5-committee-dont-reduce-the-criteria-for-an-autism-spectrum-disorder-in-the-dsm-5); see also Lutz, 2013).

In the following section of the paper we explore contrasting/contraposing and intersecting notions of autism, from intercontextual and interdisciplinary perspectives in order to examine the epistemic communities of knowledge about the ‘disorder’ through two epistemic tensions: neuro culture and personhood and what it means to be human.

### ‘Neuro culture’ and autism

Research on autism produced within the Anglo-American tradition (including Australia, as well as Sweden and other Western European countries) is dominated by neuro-biological perspectives. Within neuro-biological discourse autism is primarily described by psychiatrists, psychologists and neuroscientists as a neuro-biological disorder, as abnormalities in social interaction, emotional expression and recognition, and communication (see for example Noterdaeme & Hutzelmeyer-Nickels, 2010). Within this tradition there have been a number of cognitive theories proposed since the late 1980s, such as weak central coherence (Frith & Happe,

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<sup>1</sup>‘Snippet’ from Jane Meyerding’s website, <http://mjane.zolaweb.com/snipframe.html>

1994), executive dysfunction (Ozonoff et al., 1991), theory of “mindblindness” (Baron-Cohen, 1995), and a neurophysiological theory of mirror neuron dysfunction (Williams et al. 2001). Such findings have been the basis of a wave of interpretations about the centrality of the fully functioning “social brain”. Social neuroscience typically uses functional neuroimaging (fMRI) to demonstrate areas of the brain that function together to enable humans to predict other people’s actions on the basis of their beliefs and desires (“theory of mind”), and understand other people’s goals, intentions and emotions (Frith & Frith, 2010). In view of this heterogeneous field of research, it has been proposed that autism is best understood as a “multi-system disorder” (Charman, 2006), with genetic aetiology and brain based abnormalities, especially in the connectivity of prefrontal cortex and amygdala (Loveland et al., 2007; Mitchell et al., 2009).

Despite this lack of coherence with respect to aetiology, contemporary research draws on several approaches to define biological markers, reflective of the dominant neurobiological focus of current research. There are three main trends: the search for the characteristics of the “autistic brain”, the quest for an autism genotype(s), and research on co-morbidity and environmental influences (Nadesan 2005). Lord *et al.* note that while there has been great hope for both structural and functional neuroimaging findings, “these approaches seldom provide data on an individual level, do not yet have well-accepted standards or replicability across time or site...and have rarely addressed questions of specificity of findings to ASD” (2012, p 491). As Nadesan (2005, p 172) points out, “the contemporary state of the research cannot provide any definitive, conclusive, and generalizable answer to the question of how autism emerges”. Neither is there consensus about the methodology to be used in clinical interventions (Feinberg & Vacca, 2000; Newschaffer & Curran, 2003). However, as Chloe Silverman notes, “although researchers have had trouble finding localized structural changes, autism has retained its identity as a genetic

disorder of the brain” (2012: 155).

Furthermore, despite the lack of consensus and difficulty in finding brain-based explanations that fully account for autism, the research continues to look for them. Central to this conceptualisation of autism as a neurobiological disorder is the shared understanding of the ‘deficient’ and ‘lacking’ nature of autism. In recent years neurobiology has become a hugely powerful way of understanding identity and citizenship (Rose & Novas, 2005), and has become powerful to the extent that it could be argued that we are living in a ‘neuro culture’ (Ortega & Vidal, 2011). Autism, commonly defined as a neuro-biological disorder and given a psychiatric diagnosis, illustrates this ‘neurobiologization’ of culture.

The ‘neurologization’ of autism produced through conventional scientific research practices, as outlined above, has been challenged in some cultural contexts. For example, a competing discourse of neurodiversity has emerged as reaction to a medicalised neurological discourse. The neurodiversity perspective also draws on neuroscience or brain based vocabulary to describe autism although with depathologising aims. Within this perspective, autism is described within a framework of neurological diversity, as one of many variations in the functionality of the human brain (Broderick & Ne’eman, 2008), including alternative social functionalities (Brownlow et al, 2015). In line with this, Doan and Fenton (2013) argue that behaviours that are constructed as ‘atypical’ and undesirable within an ‘neurotypical’ (NT), or non-autistic (Attwood, 1998), understanding of the world, including hand-flapping, repeatedly ordering objects (e.g., toys) in rows, and profoundly restricted routines, have a function or purpose for the person with autism and hence are a valuable activity.

The concept of neurodiversity can serve to challenge cognitive normalcy and to offer alternative, positive, interpretations of autism and autistic identity. Neurodiversity discourse

enables a challenge to dominant understandings of autism as a neurological *deficit*, instead focusing on autism as neurological *difference*. It also offers a way of naming non-autism and rendering visible power structures that naturalise an NT world. The discourse has been widely drawn on, in some cultural spaces, by social movements dominated by adults with autism (Broderick & Ne'eman, 2008). For neurodiversity activists, the power of neuroscience serves to legitimise autism as a positive state rather than a deficit and provides a powerful mechanism for securing social rights and gaining political recognition (Ortega, 2013). Hence, the appeal to neurological bases of autism potentially allows critical autism studies to engage with the biological register in a non-reductionist or medicalised way, which fosters deficit-focused narratives of autism. Engaging with biology here means opposing the medical model of disability and to bolster one's sense of identity that may help to erase the social stigma often associated with mental pathology and open up to non-pathologising ways of being.

In the UK, discourses of neurodiversity are embedded in everyday understandings of autism and in professional practices (Runswick-Cole, 2014). Similarly, in Sweden the autistic self-advocacy movement has particularly drawn on neurodiversity discourse, where notions of neurodiversity are mobilised to argue for more autism-friendly and adapted work places (Bertilsson Rosqvist, manus). It has travelled less through other cultural contexts, such as Brazil, Australia and Canada. Thus we are interested in how it has moved and gained currency in some contexts but not others. Further we are interested in its potential and limitations both as a theoretical concept and as an 'object' already 'out there' to be explored. As a theoretical concept it can be used to explore alternative, more ability-informed understandings of autism, offering a critique of dominant discourse and a way of naming and scrutinising cognitive normality and NT-dominated perspectives.

The recourse to a ‘brain based’ discourse in which to locate an explanation of diversity rather than a deficit view of autism, is however not without its difficulties. The cerebralisation of autism, as invoked in the neurodiversity discourse, can be used to produce non-pathologised forms of identity and community, however it may also lead to a reductionist identity politics, which can narrow important aspects of personhood and reify identity (Ortega, 2013). Furthermore, the discourse may produce essentialised entities; an ‘us and them’, which creates unfruitful barriers between different kinds of advocates (Runswick-Cole, 2014). Our interest, however, is in how neurodiversity has been adopted in - and adapted to - some contexts as a way to reframe debates about autism (as in the UK) and for political change (as in Sweden).

### Cognitive normalcy and being human

On December 3<sup>rd</sup>, 2013, Swedish national radio broadcast a report about a man diagnosed with autism, who for more than one year had been isolated in a room at the forensic psychiatric regional clinic in the small Swedish town of Växjö. During this entire period, the staff had communicated with the man only through a small hatch in the door, and when he was occasionally allowed to come out into the exercise yard, none of the members of the staff were present. To federal counsel Hanna Jarvad at the Swedish National Society of Autism [Autism och Asperger-förbundet] it was obvious that the man was being mistreated, that the so-called care he received was based on ignorance and could in fact only be expected to worsen the symptoms of his autism. (Sveriges Radio) Surprisingly, this report did not induce any reaction

from the public or the medical experts, even though the man's treatment contravenes not only Swedish legislation, but also the United Nations Declaration of Human Rights (UN).<sup>2</sup>

In Brazil, the newspaper *O Globo* published an article in July 2006, denouncing the existence of many autistic individuals in Brazil who spent their lives confined in empty rooms, locked in basements, frequently tied up. As child neuropsychiatrist Raymond Rosenberg states, 'Unfortunately, they are "the children of the basement". They spend their lives hidden, locked. It used to be like that and is today as well. We have even seen cases of chained boys' (cited in Aggege, 2006, p 18).

These stories demonstrate the fragility of citizenship rights for people with autism (c.f. Bertilsdotter Rosqvist et al, 2014) and the possibility of failing to qualify as 'human' (Bergenmar et al, 2015; Goodley et al, 2014). Following Judith Halberstam and Ira Livingston (1995), it can be argued that becoming human, or being recognised as human, can be seen as a process of qualification, including a struggle, for groups in the borderland of cognitive normality and cognitive normates (ie non-autistic people) (Garland Thomson, 1997). The Swedish and Brazilian examples above remind us that people with autism are still, in many cultural contexts, treated as not just deficient in skills and abilities but as less than human and subject to 'inhuman' treatment. We are interested in how humanizing and dehumanizing practices present in different contexts, particularly in how neurotypicality is produced as 'ability' in contrast to autism, and autistic traits produced as 'disability' whilst neurotypical traits are made intelligible, natural and human. The cultural production of childhood and 'development' demonstrates how culturally

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<sup>2</sup> The narrative was initially written and developed by Ann-Sofie Lönngrén (Ph.d. and Associate Professor (Docent) in Literature, Center for Gender Studies, Uppsala University, Sweden) as part of a joint research application between Lönngrén, Jenny Bergenmar and Hanna Bertilsdotter Rosqvist. Lönngrén has kindly given her permission to draw on this narrative in this paper.

specific ideas about being human are translated into developmental science and the production of essentialised truths about ‘appropriate’ forms of development. Ideas about normative childhood and adulthood impact powerfully, and negatively, on children and adults with autism and their families (See for example Burman, 2008; O’Dell & Brownlow, 2015).

A critical approach to understanding autism reveals how the construction of autistic and neurotypical traits and identities holds important insights for how to rethink ideas, for example of ‘real’ humans and human citizenship, associated with and conditioned by cognitive normalcy. Nadesan (2005) proposed that ‘socially constructed standards of normalcy embedded in cultural values and practices not only shape our interpretations of autism, but also contribute to the production and transformation of people labelled with the disorder’ (Nadesan 2005, p 9). Within taken-for-granted assumptions about being human is the production of particular ways of ‘doing social’ (sociability or sociality) (c.f. Ochs & Solomon, 2010, Brownlow et al, 2015). Differences in sociability/sociality or social functionality have a dramatic impact on the social, cultural and legal position of the individual. Thus, ‘correct’ (i.e. non-autistic notions of) social functionality and emotionality appear to be central to Western definitions of humanity (see for example Smith, 2007; Bourke, 2011).

### Conclusions: Intercontextual understandings and voices

We conclude by reflecting on the agenda set by Davidson and Orsini (2013) to develop themes and analytics that can extend critical thinking around autism and the emerging field of critical autism studies. In thinking critically about autism we argue the following points need to shape the framework for a critical autism approach:

- *Recognize that ‘autism’ is both a diagnostic category and lived experience that shifts through different cultural contexts.*

A challenge for critical autism studies is to take seriously how intercontextual understandings of autism shape the lived experience of autism, as well as the diagnosis category itself, and to do this without recourse to a traditional (positivist) cross-cultural perspective. We view intercontextual understandings and different epistemic communities of knowledge/experience of autism as key markers of the multiplicity of autism, and an opportunity to rethink our own theoretical assumptions about culture, knowledge, and identity. Contrasting representations of autism worldwide could be used as a springboard to interrogate normative assumptions of humanness, ability, social and cognitive normalcy. Further, it enables us to explore different contexts and identify what is being included in understandings of autism and what is left out.

- *Rethink autistic identity production within sociocultural contexts.*

The analytic of epistemic communities can be useful to theorise and account for multiple perspectives and experiences rather than assuming that autism (or any other identity or experiential category) is a singular category or experience. Since our starting point is that identity is produced within specific sociocultural contexts, this is a key priority for us (see also, Davidson & Orsini, 2013). It is imperative that critical autism approaches account for the experience of people with autism who reject identity categories outright, or who think about their identities in fluid ways that defy way rigid constructions of identity that might be advanced by more conventional accounts in disability scholarship. If we fully appreciate the importance of intersectional analysis and multiple forms of oppressions, an autistic

identity might be one of a number of ways in which individuals understand their experience on the autism spectrum.

- *Examine the impacts of state provision and the economics of support/welfare.*

A comparative approach enables critical autism studies to examine the ways in which dominant neuro-biological constructions of autism (that span our cultural contexts and are evident in others internationally) take on different forms within different care systems and hence shape provision. Depending upon the definition and the pathology model in use, different treatments are provided (Block & Cavalcante, 2014, Cavalcante, 2003). For example, in Sweden the support offered is guided by the “normalization principle” in which it is stressed that “everyone is of equal value and has equal rights” (National Board of Health and Welfare [NBHW], 2009) at the same time as what is normal and what is included in a normal life is defined from a non-autistic perspective. These principles guide policies and programmes in the field of autism, such as support for finding employment in which being an adult citizen is intimately linked to engagement in work. This might be beneficial for some, but it narrowly constructs productivity and citizenship in neoliberal terms of one’s contribution to the work force. For example, the challenge in Sweden is how to reconcile an approach to welfare state support for people with autism that is guided by a care ethic stressing the rights of disabled people to meaningful employment and participation in society, with an increasingly neoliberal approach that measure one’s productivity in terms of labour force participation, stressing the obligation for all citizens to participate in society through work (Nouf et al, manus). It is clear that governments and financial

constraints are significantly affecting the level of support offered for those who need it. In Canada, for instance, where citizens enjoy universal health insurance, recent legal cases have tested the requirement to provide care for children on the autism spectrum (Orsini, 2009; Orsini and Smith, 2010). In the UK changes to the ‘welfare’ system has eroded significantly support and provision for disabled people including those with autism.

- *Explore the impacts of intervention approaches.*

The importance of the wider epistemological frameworks is evident in framing the intervention exchanges between people with autism and professionals. For example, in Brazil autism is viewed through both a psychoanalytic and psychiatric frame (Couto, 2012; Nunes, 2014; Pinto, 2005). Psychiatric services do not provide specialist services for autism, but autism is still seen as a psychiatric disorder, with the privileging of psychoanalytic approaches to autism. In Brazil, broader understandings of the categorisation of autism as either a psychosis or a disability, are also central, and have become a polarising issue, and different interventions tend to hinge on the disease-based model in use (Block and Cavalcante, 2014; Rios and Costa, 2015).

Through this paper we have argued that an intercontextual approach places autism within particular cultural-institutional contexts whilst also examining the ways in which autism as a concept/discursive product moves through different cultural locations, instead of being reduced to a series of universal characteristics or truths. A transnational focus must also build on the increasing interest among disability studies scholars in knowledge in and perspectives from the

global south, especially approaches that account for the enduring role of colonialism and racism in producing disability (see discussion in Meekosha and Shuttleworth 2009). As they correctly point out, “Although living in a world where race, racism, nationalism and globalisation are dominant forces, disability studies largely avoids these issues” (Meekosha and Shuttleworth 2009, 64)Foregrounding intersectional approaches to autism can help us to critically engage with notions of ability (and competence), and the normative production of ability through representations of a disabled ‘other’ (c.f. DeShong, 2012; Goodley, 2014), which exclude a more diverse way of defining ability. Critical autism studies requires both an abilities-perspectives (rather than a focus on deficits) to explore counter-hegemonic, alternative discourses of autism - and a critical perspective on the hegemonic discourses in which the normative productions of ability produce autism and autistic traits as deficits and lack. A critical perspective to autism should avoid reifying neurology or brain-based discourses of neurodiversity, but rather view these discourses as shaping and co-constituting autism (and neurotypicality). We need to theorise ability in its many forms, and advance approaches that enable people with autism with a range of abilities to co-produce knowledge about autism.

## References

- Aggege, S. (2006). A vida segregada do brasileiro autista, *O Globo*, 16 July: 18.
- Attwood, T. (1998). *Asperger’s syndrome: A guide for parents and professionals*. London: Jessica Kingsley Publishers.
- Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of mind*. Cambridge, MA: MIT Press/Bradford Books.
- Bergenmar, J., Bertilsdotter Rosqvist, H. & Lönnngren, A.-S. (2015). Autism and the question of the human – normative subjects and the significance of emotions and interaction in research and life writing. *Literature and Medicine*, 33, 1.

- Bertilsdotter Rosqvist, H., O'Dell, L. & Brownlow, C. (2014). The citizen-worker: Ambivalent meanings of 'real jobs', 'full citizenship' and adulthood in the case of autistic people. *The Australian Community Psychologist*, 26, 1
- Bertilsdotter Rosqvist, H., Brownlow, C., & O'Dell, L. (2015). "An association for all" - notions of the meaning of autistic self-advocacy politics within a parent-dominated autistic movement. *Journal of Community & Applied Social Psychology*, 25, 3, 219–231.
- Bertilsdotter Rosqvist, H (manus). 'Looking like you're working' – exploring notions of 'employability' and the autism-friendly workplace among autistic self-advocates in Sweden.
- Block, P. and Cavalcante, F.G. (2014) "Historical Perceptions of Autism in Brazil: Professional Treatment, Family Advocacy, and Autistic Pride, 1943–2010," in Burch, S. and Rembis, M. (Eds.). *Disability Histories*. Chicago: University of Illinois Press.
- Bourke, J. (2011) *What it Means to be Human: Reflections from 1791 to the Present*. London: Virago.
- Broderick, A. A. & Ne'eman, A. (2008). Autism as metaphor: narrative and counter-narrative, *International Journal of Inclusive Education*, 12, 5-6, 459-476.
- Brownlow, C., O'Dell, L. & Bertilsdotter Rosqvist, H. (2015) Neurodiverse spaces: Exploring the potential for social networking among people with autism, deconstructing dominant ideas of 'friendship', *Scandinavian Journal of Disability Research*, 17, 2, 188-193
- Burman, E. (2008). *Deconstructing Developmental Psychology*, 2<sup>nd</sup> edition. London Routledge.
- Cavalcante, F.G. 2003. *Pessoas Muito Especiais: a construção social do portador de deficiência e a reinvenção da família*. Rio de Janeiro: Fiocruz.
- Chamak, B. and Bonniau, B. (2013) Changes in the Diagnosis of Autism: How Parents and Professionals Act and React in France. *Culture, Medicine and Psychiatry*, 37,3:405-26.
- Chamak, B. (2014) "Autism as Viewed by French Parents", in Patel, Vinood B., Preedy, Victor R. and Martin, Colin R. (Eds.). *Comprehensive Guide to Autism*. New York: Springer.
- Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organizations. *Sociology of Health & Illness*, 30, 76–96.
- Charman, T. 2006 ) Autism at the crossroads: Determining the phenotype matters for neuroscience. *Nature Neuroscience* 9, 10, 1197.
- Couto, M.C.V. 2012. *Política de Saúde Mental para crianças e adolescentes: especificidades e desafios da experiência brasileira (2001-2010)*. Ph D. Dissertation. Institute of Psychiatry. Federal University of Rio de Janeiro.
- Curran, M. (2014). A Historical Journey Through Autism Spectrum Disorders in the Wake of DSM–5: A Review of the Journal of Autism and Developmental Disorders, 1971–2012.

Unpublished Master thesis in Clinical Psychology, University of South Queensland.

Davidson, J. & Orsini, M. (2013) Critical autism studies: Notes on an emerging field. In J. Davidson & Orsini, M., eds (2013). *Worlds of Autism: Across the Spectrum of Neurological Difference*, Minneapolis, University of Minnesota Press. 1-30.

Davis, L. (1995) *Enforcing Normalcy: Disability, Deafness and the Body*. London and New York, Verso

DeShong, S. (2012). On (post)human (dis)ability. *Subjectivity*, 5, 265–275.  
doi:10.1057/sub.2012.15

Doan, M. & Fenton, A. (2013) Embodying autistic cognition: Towards reconceiving certain 'autism-related' behavioural atypicalities as functional. In Jami L. Anderson, J.L. & Cushing, S. (eds) *The Philosophy of Autism*. New York: Rowman and Littlefield Publishers, Inc., 2013: 47-71.

Feinberg, E., & Vacca, J. (2000). "The drama and trauma of creating policies on autism: Critical issues to consider in the new millennium". *Focus on Autism and other Developmental Disabilities*, 15, 3, 130–137.

Frith, U. and Frith, C. (2010) The social brain: Allowing humans to boldly go where no other species has been. *Philosophical Transactions of the Royal Society B* 1537,365, 165–176.

Frith, U. and Happe', F. (1994) Autism: Beyond 'theory of mind'. *Cognition* 50, 1–3: 115–132.

Garland-Thomson, R. (1997) *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*. New York: Columbia University Press

Goodley, D. (2014) *Dis/ability Studies. Theorizing disablism and ableism*. Taylor and Francis.

Goodley, D; Lawthom, R. & Runswick-Cole, K. (2014) Dis/ability and austerity: beyond work and slow death, *Disability & Society*, 29:6, 980-984

Goodley, D. (2013) Dis/entangling Critical Disability Studies. *Disability & Society* 28, 5: 631-644

Hacking, I. (1995) 'The Looping Effects of Human Kinds', in D. Sperber, D. Premack and A. James-Premack (eds) *Causal Cognition: A Multidisciplinary Approach*, Oxford: Clarendon Press

Hacking, I. (2002) 'Making up people', in *Historical Ontology*, Cambridge, Mass: Harvard University Press.

Halberstam, J. & Livingston, I. "Introduction: posthuman bodies." In *Posthuman bodies*, edited by J. Halberstam and I. Livingston. Bloomington & Indianapolis, 1995.

Lord C., Jones R. M. (2012). "Annual research review: re-thinking the classification of autism spectrum disorders", *Journal of Child Psychology & Psychiatry*, 53, 490–509

Loveland, K.A., Bachevalier, J., Pearson, D.A. and Lane, D.M. (2008) Fronto-limbic functioning in children and adolescents with and without autism. *Neuropsychologia* 46, 1, 49–62.

Lutz, Amy S.F. (2013). “You Do Not Have Asperger’s: What psychiatry’s new diagnostic manual means for people on the autism spectrum,” *Slate*, May 22.  
[http://www.slate.com/articles/health\\_and\\_science/medical\\_examiner/2013/05/autism\\_spectrum\\_diagnoses\\_the\\_dsm\\_5\\_eliminate\\_asperger\\_s\\_and\\_pdd\\_nos.html](http://www.slate.com/articles/health_and_science/medical_examiner/2013/05/autism_spectrum_diagnoses_the_dsm_5_eliminate_asperger_s_and_pdd_nos.html)

Meekosha, H. & Shuttleworth, R. (2009) What’s so Critical About Critical Disability Studies? *Australian Journal of Human Rights* 15, 1, 47-76

Mitchell, S.R., Reiss A.L, Tatusko DH, Ikuta I, Kazmerski DB, Botti JA, Burnette CP, Kates WR. (2009) Neuroanatomic alterations and social and communication deficits in monozygotic twins discordant for autism disorder. *American Journal of Psychiatry* 166, 8, 917–925.

Nadesan, M. (2005) *Constructing Autism: Unravelling the ‘Truth’ and Understanding the Social*. London/New York: Routledge.

The National Board of Health and Welfare (NBHW) (2009). Swedish disability policy – service and care for people with functional impairments. Available at:  
[http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188\\_2009126188.pdf](http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/8407/2009-126-188_2009126188.pdf) [2013-10-27].

Newschaffer, C.J., & Curran, L.K. (2003). Autism: An emerging public health problem. *Public Health Reports*, 118, 5, 393–399.

Noterdaeme, M. & Hutzelmeyer-Nickels, A. (2010). Early symptoms and recognition of pervasive developmental disorders in Germany. *Autism*, 14, 575-588.

Noof, F., Bertilsdotter Rosqvist, H. & Markström, U. (manus) Fit for any work? - exploring meanings of ideal and anti-ideal jobs among people with high functioning autism.

Nunes, F.C.F. (2014) Atuação política de grupos de pais de autistas no Rio de Janeiro: perspectivas para o campo da saúde. Master Dissertation. Institute for Social Medicine. State University of Rio de Janeiro.

O’Dell, L. & Brownlow, C. (2015) ‘Normative development and the autistic child’ p296-309 in O’Reilly, M. & Leseter, J. (eds) *The Palgrave handbook of child mental health*. Hampshire, UK. Palgrave Macmillan

Ochs, E. & Solomon, O. (2010). Autistic sociality. *ETHOS*, 38, 1, 69-92.

Orsini, M. and Smith, M. (2010) ‘Social movements, knowledge and public policy: the case of autism activism in Canada and the US.’ *Critical Policy Studies*. 4, 1, 38-57.

Orsini, M. 2009 ‘Contesting the Autistic Subject: Biological Citizenship and the Autism/Autistic Movement’, in S. Murray and D. Holmes (eds) *Critical Interventions in the Ethics of Health Care*, London: Ashgate Publishing.

- Ortega, F. & Vidal, F. eds, 2011 (eds) (2011) *Neurocultures: Glimpses into an Expanding Universe*, Frankfurt and New York: Peter Lang.
- Ortega, F. (2013). "Cerebralizing Autism within the Neurodiversity Movement: A Challenge for Critical Autism Studies?" In: J. Davidson and M. Orsini (Eds.). *Critical Autism Studies: Enabling Inclusion, Defending Difference*. Minneapolis: University of Minnesota Press.
- Ozonoff, S., Pennington, B.F. and Rogers, S.J. (1991) Executive function deficits in high-functioning autistic individuals: Relationship to theory of mind. *Journal of Child Psychology and Psychiatry* 32, 7: 1081–1105.
- Pothier, D. & Devlin, R. (2006) *Critical Disability Theory. Essays in Philosophy, Politics, Policy and Law*. Vancouver: The University of British Columbia Press
- Rios, C. and Costa, B. (2015) The changing face of autism in Brazil. *Culture Medicine and Psychiatry*, 39,2. DOI:10.1007/s11013-015-9448-5 .
- Rose, N. & Novas, C. (2005) "Biological citizenship" in A. Ong & S. Collier (eds) *Global Anthropology*. London: Blackwell.
- Runswick-Cole, K. (2014) 'Us' and 'them': the limits and possibilities of a 'politics of neurodiversity' in neoliberal times, *Disability & Society*, 29:7, 1117-1129, DOI: 10.1080/09687599.2014.910107
- Silverman, C. (2012) *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton: Princeton University Press.
- Smith, R. (2007) *Being Human: Historical Knowledge and the Creation of Human Nature*. Manchester: Manchester University Press
- Whelan, E. (2007). 'No one agrees except for those of us who have it': endometriosis patients as an epistemological community, *Sociology of Health & Illness*, 29, 7, 957–982.
- Williams, J.H.G., Whiten, A., Suddendorf, T. and Perrett, D.I. (2001) Imitation, mirror neurons and autism. *Neuroscience & Biobehavioral Reviews* 25(4): 287–295.