

ORCA - Online Research @ Cardiff

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository:https://orca.cardiff.ac.uk/id/eprint/76424/

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Fitzgerald, Des 2014. The trouble with brain imaging: hope, uncertainty and ambivalence in the neuroscience of autism. BioSocieties 9 (3), pp. 241-261. 10.1057/biosoc.2014.15

Publishers page: http://dx.doi.org/10.1057/biosoc.2014.15

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See http://orca.cf.ac.uk/policies.html for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



The trouble with brain-imaging: hope, uncertainty and ambivalence in the neuroscience of autism

Des Fitzgerald Cardiff University FitzgeraldP@cardiff.ac.uk

This is a pre-print (i.e. the version before peer review) of an article published in *BioSocieties*. The definitive publisher-authenticated version [Fitzgerald, D. (2014) 'The trouble with brain-imaging: hope, uncertainty and ambivalence in the neuroscience of autism', *BioSocieties*, 9: 241-261 is available online at: http://www.palgrave-journals.com/biosoc/journal/v9/n3/abs/biosoc201415a.html doi:10.1057/biosoc.2014.15

Abstract:

This paper is about ambivalent dynamics of hope and uncertainty within neurobiological autism research. While much literature has commented on the positive hopes and expectations that surround technoscientific projects (van Lente and Rip, 1998; Brown et al., 2000) few have focused on less promissory visions – and, in particular, on the presence of uncertainty, as well as unease and disappointment, among working scientists. This paper shows how autism neuroscientists actually talk about their research in ambivalent, entangled registers of both promising hope and disappointed uncertainty. The paper locates the dynamic between these in an 'intermediate terrain' of autism research – in which autism is both 'present' as an epidemiological and social force, but also 'ambiguous' as a (not yet) well-defined clinical and scientific object. It argues that neuroscientists work through this terrain by drawing not only on a discourse of unalloyed hope and promise, but by entangling their research within a more complex register of 'structured ambivalence,' which includes languages of uncertainty, unease and disappointment. As well as showing the novelty of research within autism's 'intermediate terrain,' this brings a new perspective to the 'sociology of expectations' (Brown and Michael, 2003) arguing for more attention to *low* expectations among scientific researchers.

Introduction

Much recent scholarship has drawn attention to the way that technoscientific projects, including those within the life sciences, are animated by discursive structures of hope, optimism, and positive expectation (van Lente and Rip, 1998; Brown *et al.*, 2000; Borup *et al.*, 2006). But there has been little sustained attention to the presence of more ambivalent scientific discourses – and the degree to which expressions of uncertainty, disappointment and unease also feature at the heart of some of these projects. For example, social-science scholars have shown how neurobiological research has frequently oriented itself to the illumination of tricky psychiatric and psychological categories, precisely through 'imagined futures' of improved diagnosis, targeted intervention, and effective biomedical therapy (Choudhary *et al.*, 2009; Vrecko, 2010; Choudhary and Slaby, 2012: 5). However, recent work by Pickersgill (2011) on promises within the neuroscience of psychopathy – where Pickersgill draws especially on his interviews with front-line scientists and practitioners – suggests that within the practice of neurobiological research, there might be rather more uncertainty, and rather less positive expectation, than has previously been identified.

In this paper, I explore some of the ways in which neuroscientific research on a psychological or psychiatric diagnosis is animated by ambivalent dynamics of hope and disappointment. Focusing in particular on neurobiological autism research, my argument is that there are spaces of neuroscientific practice that are not only propelled by a promissory vision, but that are entangled within a much more dynamic imaginary of promising hope and disappointed uncertainty. I argue that as much as a 'sociology of expectations' (Brown and Michael, 2003) has taught us about the generative role of *promise* in the life sciences, expressions of these more negative expectations are not

only thickly present within neuroscientific research, but they may actually be important for the maintenance of particularly ambiguous neuroscientific projects.

Autism research is ideal for thinking about these dynamics. If, in recent decades, autism has dramatically increased in diagnostic prevalence (Baron-Cohen *et al.*, 2009; CDC, 2012), has emerged as a figure of popular and political concern (Murray, 2008: 2; Great Britain, 2009), and has also become a growing site of social action and contest (Bumiller, 2008; Hart, this issue), the specificity of its biological manifestations, and especially that of its *neuro*biology, remain stubbornly outside the grasp of researchers (Lord *et al.*, 2012: 491). In this special issue, contributing authors have identified an 'intermediate terrain' formed by these gaps, a set of novel biological and social possibilities that have emerged from the co-presence of uncertainty and visibility (Guest editors' introduction, this issue). Around the still-emerging category of autism, a productive space has emerged for scientific, medical and political actors, as well as people diagnosed with autism and their allies, to actually reconfigure and rethink the ways that complex, biosocial spaces of research, action and care are structured and held together (ibid.).

In this paper, I argue that within this terrain we can also see the emergence of a novel way of relating neuroscientific research to imagined futures. I show that neurobiological autism researchers certainly trace their scientific interest through a promissory logic of hope and expectation; but also, sometimes, they work through parallel registers of disappointment, unease, and anxiety. I am not arguing that autism neuroscience is doomed or hopeless, or that its researchers are overwhelmingly marked by despondency and disillusion. My argument is that the 'intermediate terrain' of autism research opens up a novel space for the future-oriented imaginary of neurobiological research, a space in which neuroscience might not only be animated

by positive expectation, but in which it may be strung between more delicate and ambivalent dynamics of hope and disappointment. This may not be unique to autism, but I argue that the 'intermediate terrain' of autism research, and the zone of unlikely alliances and loops that surrounds it, makes autism a potent site for seeing this complexity.

To make this argument, I will first use published accounts to demonstrate the increased social presence of autism, but also the sense of uncertainty that surrounds neurobiological autism research. In the rest of the paper, I will draw on data from thirty-seven semi-structured qualitative interviews that I conducted with UK-based autism neuroscientists (including a small number of third-sector funders and organisers) between 2010 and 2011. First, I use this material to show that autism research is indeed frequently narrated through languages of hope and expectation – and particularly through the excitement of finding a biomarker for autism, and of uncovering autism as an essentially organic phenomenon. In the subsequent section, however, I show that there is also a strong current of disappointment in, and anxiety about, the methods and assumptions that are built into neurobiological autism research. But my argument will not be that these parallel dynamics are contradictory or problematic. I will suggest, instead, that they are embedded in the complexity of doing neurobiological research on a diagnostic phenomenon marked by both presence and ambiguity. They reflect the novelty with which autism researchers move through some ambiguous terrain, as well as the ambivalence with which they reflect on it.

Ambiguity and presence

If you ask a neuroscientist what autism is, they might tell you that autism is a complex neurodevelopmental spectrum disorder with characteristic deficits in three domains:

social interaction, communication, and repetitive behaviour (APA, 2000). They might also mention that autism is strongly heritable (Bailey et al., 1995), that it is diagnosable in about one in one-hundred school-age children (Baron-Cohen et al., 2009), and that, in the UK, it costs the economy about £34 billion every year (Knapp, 2012). But then, after a pause, they might tell you that none of this is either straightforward or uncontested. For one thing, proposed changes to the Diagnostic and Statistical Manual of Mental Disorder (DSM) would remove communication from the three domains, and would also collapse the distinction between autism and cognate diagnoses like Asperger's Syndrome (APA, 2011). The one in one-hundred figure may have to be revised too – a March 2012 report from the Centres for Disease Control, in the United States, increased this to one in eighty-eight (CDC, 2012), while the £34-billion cost, already a notable increase from a 2009 estimate (Knapp et al, 2009), is described as 'tentative' (Knapp, 2012). More to the point, perhaps, there is also now some disagreement about whether the triad, causally, actually composes a single neurodevelopmental disorder (Geschwind and Levitt, 2007; Happé and Ronald, 2008), while the 'specific genetic etiology' of autism, after more than a decade of research, 'remains largely unknown' (Gupta and State, 2007: 429). Skating across all of this, there are also now political contests over whether we might characterize autism as a 'disorder' in the first place – and even if it might not, in some way, mark certain talents or advantages (Ortega, 2009; Happé and Frith 2010). 'We know more about autism now than at any point in history,' says the cultural historian and autism parent, Stuart Murray, 'yet, at the same time, if we're honest, the foundational observation that we might make, the "central fact" about autism with which we should probably start, is that we don't know very much about it at all' (2012: 1).

What has perhaps remained most striking about autism is that even as it has emerged as a focus of popular and political concern, even as it is located within both the bodies and habits of an ever-larger number of people, even as more and more research paradigms are brought to bear on it, and even, therefore, as its 'presence' as a phenomenon that 'cannot, and will not, ultimately be removed' becomes more solidified – so has autism continued to resist any sort of easy clinical or biological definition (Murray, 2008: 16). This is a significant part of what has been described in the introduction to this special issue as the 'epistemic murk' of autism research. There is a yawning gap between, on the one side, the prominence of autism as a clinical, epidemiological and social force, and, on the other side, what can be said with any certainty about autism as a neurological, genetic or diagnostic object. This gap has created a complex space of biosocial possibility: for example, just as new ways of thinking about the biology of autism's dispersed and variable genetic markers may eventually come to mark out new kinds of people (Navon, 2011), so might the space of political contest around emerging categories of autistic identity be enrolled in new forms of neurobiological essentialism, but now somewhere far from the laboratory (Ortega and Choudhary, 2011). For a diagnosis that seems most likely to mark a disorder of brain development, this gap is particularly vivid in the space of neurobiological research. In an exhaustive recent review, Lord et al. noted that while there had been great hopes for both structural and functional neuroimaging findings, 'these approaches seldom provide data on an individual level, do not yet have wellaccepted standards or replicability across time or site...and have rarely addressed questions of specificity of findings to ASD' (2012: 491). In other words, and despite some years of research, we still lack a convincing, well-replicated brain-based autism biomarker. And yet, as Chloe Silverman points out, 'although researchers have had

trouble finding localized structural changes, autism has retained its identity as a genetic disorder of the brain' (2012: 155). This leaves neuroscientists in an awkward place: unable to tack autism to an emerging project of 'neuroreductive' certainty (Martin, 2004), neuroscientists are equally unable to simply ignore both the evidence and the desire for a neurogenetic basis to the disorder (Yates, 2010).

How do autism neuroscientists work through this terrain? My suggestion is that one novel method that autism neuroscientists have drawn upon is a delicate reconfiguration of the relationship between research and hope. Since at least 'the decade of the brain,' the broad field of 'neuroscience' has been associated, internally and externally, with defining discourses of confidence and promise (Andreasen 2001; Ortega and Vidal, 2010). But it has only recently been noted that the neuroscientists who labour within this field may be inflected with more anxiety, unease, and ambivalence. In his analysis of the 'technosomatic imperative' of the new brain sciences, for example, Pickersgill (2011) has pointed to a 'promissory discourse' that structures the relationship between psychopathology, technology, and the body. But he also argues that this does not tell the whole story:

The embedding of this therapeutic promise within the talk and practice of scientists and mental health professionals is far from straightforward...neuroscience engenders considerable ambivalence, expressed both by clinicians and scientists themselves (ibid.: 460).

In the rest of this paper, I want to use the gaps and possibilities that surround autism neuroscience to build on this suggestion. In particular, and drawing on my interviews with autism neuroscientists, I want to show how researchers narrate their own expectations through an ambivalent dynamic of both promise *and* unease. My goal is not to operationalize specific kinds of negative expectation (identifying, e.g. particular

roles for 'disappointment' or unease' in themselves), but to point to a broader presence of low expectation, characterised by the repeated use of these – and related – discursive registers. My core argument is that sustaining and managing an ambivalent dynamic between such hopeful and disappointed registers is what allows neurobiological autism researchers to work within a space characterised by both presence and ambiguity. I argue that this dynamic is another instance of the novel possibilities engendered by the strange terrain of autism research – but one that also may call for wider attention to structures of disillusion and disappointment within neuroscience.

The dream is to intervene

When I began interviewing autism neuroscientists, I initially found that their talk was often shot-through with rich discourses of hope, possibility and positive expectation. Of course, the study of mental disorder has often been structured by a sense of therapeutic hope for the future (Moreira and Palladino, 2005). For the more complex neurodevelopmental disorders, this hope has recently become embedded in the search for brain-based biomarkers particularly – and in the emergence of neuroscientific technologies that might mark these out (Raff, 2009). In the first pages of the first issue of *Nature* published this decade, for example, the editors self-consciously framed the 2000s as 'a decade for psychiatric disorders,' a sense of optimism and expectation that was precisely rooted in the idea that 'new techniques — genome-wide association studies, imaging and the optical manipulation of neural circuits — are ushering in an era in which the neural circuitry underlying cognitive dysfunctions...will be delineated' (Nature, 2010:9). The authors went on, citing the US National Institutes of Mental Health (NIMH) head, Thomas Insel:

'whether for schizophrenia, depression, autism or any other psychiatric disorders, it is clear...that understanding of these conditions is entering a scientific phase more penetratingly insightful than has hitherto been possible' (ibid).

I am not interested in assessing the accuracy of such claims. Instead, I am focused on the degree to which these kinds of hopes, common enough in a public-facing literature, were mirrored by the frontline researchers that I spoke to. 'What intrigued me in the early days about MEG [Magnetoencephalography],' said one brain-imager that I interviewed, who had been involved in quite a few studies of autism,

is that, first of all, it is a beautiful combination of quantum physics, which is the underlying principle of the scanner, and the application to not only biological, but human, and even psychiatric problems, or neurological problems...it was sort of immediately a very sort of appealing way of having the dynamics of the human brain measured with a tool which is capable of capturing these dynamics.

This view, that technologies like MEG would open up the human brain, and give new insight into psychiatric and neurological problems, was not uncommon: 'all the neurology-type people are looking for the biomarker, you know,' one professor of psychology told me, '... and I think they have implicitly in their heads this notion that we will find something which will then [makes a whooshing noise] it'll part like the Red Sea.' Or as a representative of a funding organisation put it:

there was a very strong sense about 5, 6 years ago...that the technologies to create the breakthroughs in conditions like autism were coming through – the neuroimaging technologies, the genetic analysis technologies, you know, and the sort of bringing to bear, if you like, of those technologies, you

know, the sort of access to brain material and the kind of imaging that you could do with brain material, and indeed the chemical procedures that you could do with brain material.

For researchers and research-funders, this technological hope of access to 'material' expresses the promise of advancing the field in some way. In the case of psychological and psychiatric autism research, this goal often manifests as an expectation of reducing the field's reliance on behavioural measures. This came up during a conversation that I had with one researcher, who was involved in innovative work to find a quantitative-organic biomarker for autism. She told me about her experience of joining her current research project on autism, and being trained to use the ADOS (Autism Diagnostic Interview Schedule), which is often used as a screening tool for research participants (Lord *et al*, 1989). 'I was amazed at how many details these people [the trainers] pick up on,' she said

like, you know, you speak about instrumental movements and so on, goal-directed actions, and I just couldn't see it. And I could only do it with a lot more training – I'm talking months here.

Her amazement at the skill required by behavioural analysis is not only a compliment to clinical skill: it is also expressive of a more fundamental surprise, i.e. that such skill would be required at all. For this researcher, there had to be a better, more predictable, way to go about this. And the best hope for this advance lay with the new brain sciences: 'If you look at the behavioural studies,' she said,

there are not too many differences on the behavioural level, when you look at adults. But there are also a few brain studies now coming out that show, actually, in terms of their anatomy, people with Asperger's are different from people with high-functioning autism... if I was a behavioural researcher, I

would feel that that [behavioural autism research] has maybe come to an end, because if we are now speaking about, actually, Asperger's or HFA [high-functioning autism] is the same behaviourally, what are we going to research on – what comes next?'

Her basic hope, therefore, is that developments in brain-imaging technology will reveal a difference in brain anatomy (between autistic and 'typically-developing' people) wider than the difference in behaviour – delineating and marking autism at a much finer level than is possible for even the most skilled clinician.

A second and related technological hope had to do with finding an anatomical pathway for new kinds of diagnosis and treatment for autism – which is characteristic of contemporary psychiatric-biomarker research in general, but is particularly acute within the realm of the neurodevelopmental disorders (Singh and Rose, 2009: 202). These two hopes, in turn, are premised on another expectation: if clinicians could intervene on the neurological substrate even before behavioural symptoms appeared, this would likely prove more effective, and more efficient in the long term. 'People with autism have got biological differences in brain development,' said one senior professor:

[...] and we've just identified what those differences are [using brainimaging]. And we're in the middle of saying 'can you use those differences to diagnose people with autism rapidly, and/or in a costeffective way?'

This was a common theme: 'the dream is to intervene prior to the onset of symptom,' another interviewee said to me, 'you know, to try and divert the developmental pathway before the full core symptoms of autism become kind of embedded in the system.' Discussions of the desire to wring early diagnosis and treatment from

neuroscience, though not present in all of my interviews, were never unsubtle.

Perhaps summing up a fairly common view, one senior figure put it to me like this:

I don't think there are many people in autism who would say that they don't want to understand other people, even if they choose not to engage with other people at that level, so I would expect that [one day] we would be able to intervene psychologically, neurologically.

The idea of treatment, especially, is controversial in autism – and particularly so the idea of intervening neurologically at a very early stage (Solomon, 2008). I didn't encounter anyone who was unsympathetic to the view that there are good reasons to be wary of these. But I still encountered, repeatedly, the hope that people with autism would be able to be diagnosed earlier and treated, in the future, specifically by acting on the brain. As Laura Schreibman points out, 'we still have no cure for autism. Yet there is reason to be hopeful' (2005: 133). I encountered many neuroscientists who still carried this hope.

Now we have all these wonderful tools

Quite a few scholars of science and technology have lately turned their attention to thinking about the role of just such positive expectations in gathering together large-scale, diverse technoscientific projects – such as the search for a brain-based biomarker of autism – and have identified some of the ways that these projects actually get justified and assembled in the present, precisely through the expression of some promise or prospect for the future (van Lente and Rip 1998, Brown and Michael 2003). In particular, scholars have identified the role of specifically *promissory* 'expectations' that get attached to scientific and technical projects, and around which resources and actors are assembled: 'technological futures are forceful,' van Lente

points out: 'once defined as promise, action is required' (2000: 59). By expectations, then, is meant 'wishful enactments of a desired future...hyperbolic expectations of future promises and potential' (Borup *et al*, 2006: 286). Thus the emphasis is mostly (although not entirely) on a collective desire to imagine something basically *good* for the future, through the assembly and propulsion of some scientific and technological practice. On the basis of this promise, it becomes reasonable, and even imperative, to enact that project or practice in the present. It is in this sense that, for these authors, expectations are thought to play a generative role in scientific contexts: they 'guide activities, provide structure and legitimation, attract interest and foster investment' (ibid.: 285-286). Indeed, as Brown and Michael (2003: 4) have argued, through the articulation and enactment of varieties of expectation, the epistemic and practical distance between the past and the future is discursively (if not materially) elided: 'the future is mobilized in real time,' they point out.

Unquestionably, this 'sociology of expectations,' although usually focused on more public discussions (Kitzinger, 2008), at least partly explains what's going on in my interviews – insofar as these expressions of hope can also be read as the outline of an assembly-practice. In this sense, the loose promise of neurological diagnosis and therapy in the future becomes the ground on which large-scale projects are enacted in the present. Brown and Michael have also noted an inverse correlation between closeness to the actual scientific practice, and the level of expressed hope (2012: 12-13). And while I found these expressions at all levels among the scientists in my interviews, from PhD students to senior professors, some of the more compelling and thought-through articulations came from the (slightly more distanced) leaders of large-scale projects – who were clearly not articulating their sense of hope for the first

time, and for whom a convincing image of expectation likely played a more directly instrumental role.

For example, when I questioned the Principal Investigator of one large project about why, exactly, someone like him, a prominent neuropsychiatrist with diverse interests, would pursue a neuroscience of autism, he imagined precisely the kind of promising-future scenario that the biomarker discourse is organised around. 'Say you go in to an accident and emergency department with a cardiac arrest,' he said:

Now, option A: you describe to me your symptoms. Crushing chest pain, burning sensation going up into your neck, pain coming down your arm, right? Feeling sweaty. Not feeling chipper. And I say to you, 'oh, really? Sounds like you might have something going on in your chest.' But you would expect me to do an ECG [Electrocardiogram] to measure the function of your heart, right? Or if you went in there thinking 'I've got diabetes,' you'd expect the doctor to measure your blood-sugar, right? If you went in there with epilepsy, you'd be expecting him to measure your brain-waves. Well why should you not be doing the same thing if you go in with a biologically-based neurodevelopmental disorder? I want to be measuring whether you've got an abnormality in the organ in question.

Here is precisely the hope of diagnosis and treatment that is invested in brain-based biomarker research, and around which that programme is organised – i.e. the hope that neuroscience will one day make autism as instantly diagnosable as a heart attack. What is also interesting about this imagined scenario is that it plots both backwards and forwards in time, to argue that the basic promise of a neuroscience of autism is to provide access – conceptual, and methodological – to the organ that researchers had really *always* been investigating, but to which methods, up to now, had been

inadequate. This is at least one part of what a discourse of expectation can do for the autism researcher particularly – which is to make sense of an awkward, troubled past and present, and to re-imagine both in the light of some visionary future (see Feinstein, 2010, or Silverman, 2012, for accounts of this history). Essentially the same view was expressed even more bluntly by another senior scientist, who also sat at the apex of a large programme of research. 'I think neuroscience always believes that psychology was always a sub-part of neuroscience,' he said,

but in the 1970s and 1980s within psychology there was a very, very strong push to, you know, not be misled by data from neuroscience. And I think it's, you know, partly a theoretical thing, partly a methods thing as well – because we didn't really have the methods, other than looking at patients with a very messy brain haemorrhage which wasn't very, you know...or doing animal studies. Now we have all these wonderful tools for functional imaging of the brain which we didn't have in those days.

Another told me how, today,

a lot of psychologists have re-directed the focus of their work onto looking at not just the cognitive basis of some kind of process like memory, or attention, or in my case, social cognition – but also the brain basis.

Again, we can see how one of the most significant promises of the new brain sciences – the use of new, 'wonderful tools' to get at 'the organ in question' and, thereof, the 'brain basis' of disorder – underpins the basic hope that runs through many autism neuroscientists' reflections on their own practice. Previous work in the 'sociology of expectations' literature tells us that these are not empty hopes, and that their articulation and re-articulation actually helps to assemble the elements of autism neuroscience in the present.

But what was also interesting about my interviews with these scientists is that hope, optimism and expectation were only one part of the story – that, at the heart of these conversations about the relationship between neuroscience and the autism spectrum, there was also a strong current of unease, and disappointment, and even some anxiety, about the developing programme of research. This moves us away from the 'expectations' literature. It also begins to tell us what is particular about autism research, and about the ambivalent boundaries of the terrain in which it is formed.

A very indirect measure

As it happens, I had rather expected to find interviewees to be at least cautious, as well as hopeful, when they talked about what could be achieved by a contemporary autism neuroscience. Indeed, despite prevailing popular and media sentiments about 'neurobiologisation,' the self-urging of restraint, and of explanatory parsimony, is a recognisable feature of the public discourse of these disciplines (Dumit 2004; Vul *et al* 2008). But still I had not anticipated the volume of negative sentiment about neuroscience, especially imaging neuroscience, and what it could or could not tell you about autism, that I heard so frequently from autism neuroscientists. Indeed, and in spite of my own self-consciously bland and uncritical presentation, neuroscientific autism researchers consistently drew my attention to, for example, the problem of false positives, the distance between what their methods measured and what they purported to measure, the degree to which neuroimaging simply replicates what is already known through other means — and even the basic inadequacy of brain-imaging to mental phenomena in the first place.

I am not claiming that any of these issues are shocking, or unknown (Hyman, 2009). In what follows, though, I argue that there is more at stake among these

interviewees than an appropriate scientific caution. Above, I showed how I encountered scientists who were given to talking about their practice within unproblematically hopeful registers of improved clinical and diagnostic intervention for people with autism. In this section, I situate this claim a bit more precisely, by reconsidering it in light of some alternative accounts of the future of autism neuroscience – and these are those accounts in which hope and promise were less strongly present, and in which the dominant tropes were things like disappointment, unease, and even anxiety.

Consider the following account, which is about functional Magnetic Resonance Imaging (fMRI) of autism in particular. It comes from a young autism researcher, whose intellectual and methodological hinterland was actually more in a hard-nosed cognitive neuroscience than it was autism research or psychology as such. 'You've got to be careful with neuroimaging and the questions you ask,' she said

because the problem with neuroimaging [is that] you'll always get a result – you'll always get some blobs, you know? [...] I always say, I used to laugh to people and say 'oh my God, this is an art, not a science' [laughs] because...you've just got to be so careful. And I think there's a real truth to neuroimaging. I believe in it. But it's one of those things that require replication – and the truth will out, and if you've done 40 studies on social cognition and 38 of them are showing the superior temporal sulcus, then I think you can hold your hand up and say, 'well this area is involved in social cognition,' which is really important, but there's a hell of a lot of other blobs, and that's not a very nuanced finding either [laughs], it's a bit crude, so I think to get...I think it's got a long way to go, and people have got to be really careful.

Here, I particularly want to note the tension between this neuroscientist's commitment to the basic truthfulness of the image, and, nonetheless, her acknowledgement of how heavily mediated the process of production is, and also how much artifice is potentially involved in the interpretation. And although this researcher finds some resolution in urging care and in deferring to replication, the nervous laughter, and her anxious doubling back even when her account seems to have achieved some basic resolution ('it's a bit crude'), suggests the presence of a deeper and more on-going unease.

This was repeated in other interviews where, in particular, technical problems with the generation, processing and handling of brain-imaging data were repeatedly forefronted. The following quote comes from a psychiatric neuroimager — who had worked on quite a few autism projects, but who also, and perhaps even more so than the person quoted above, was intellectually embedded in the hard science of brain-imaging analysis. Lamenting the generally weak understanding of the physics of these technologies among psychiatrists and psychiatric researchers, he drew particular attention to the phenomenon of resting-state data. The resting-state data came about,' he said,

because people started thinking about so-called deactivations, and noticing that these deactivations were appearing in virtually every dataset. And people ignored them. People literally airbrushed them out of their results. They just didn't want to know.

I was struck, at the time, by how scathing this interviewee was about people's use of the method ('they just didn't want to know'), and also how irredeemably problematic he found the method in general ('virtually every data-set'). This is not a story about the need for proper scientific caution; nor is it a story about the basic scientific

pragmatism and scepticism that often override tempting rhetoric about the objectivity of brain-imaging. This interviewee went on to argue that the growth of brain-scanning had less to do with the hope of more accurate accounts of diagnoses like autism, and much more to do with cynical self-interest within the political economy of the contemporary academy: 'If you're just sitting in an office writing things down on a piece of paper,' he said,

that might be great research, but doesn't necessarily bring in much income. What brings in income is doing big studies that employ lots of people, then those people become dependent on your goodwill, and so then you have influence on them. And so obviously that's the way it works. The huge increase in scanning, of course, people are thinking that would be a way to get power and influence by, you know, bringing in research money and so on and so on.

Although this situation of technology within the politics of the university is probably not so rare — it is striking to have this view narrated through the large-scale advent of brain scanning, in particular. Moreover, this interviewee's unease, about what was really at stake in large-scale brain-imaging of diagnoses like autism, was matched by a broader disappointment in what this imaging practice could realistically achieve: 'brain imaging is based on a lot of assumptions,' sighed a postdoc that I interviewed, 'you know you must be measuring something in the brain...but it's correlates of that thing.' Or as another expressed the same view: 'fMRI is a very strong [technology]...but it is a very indirect measure.'

I am not positioning these as counter-examples to the 'sociology of expectations' literature – which acknowledges both that 'expectations' are not always positive, and also that even positive imagined futures will generally co-exist with

some sense of failure, or simply frustration. As Borup and his colleagues put it: 'disappointment seems to be built into the way expectations operate in science and technology' (2006: 290; see also Rosengarten and Michael, 2009, for an example of the way that expectations can form and re-form around changeable scientific objects). There is certainly space within the 'expectations' model to theorise the place of more negative expectations in the way that scientific projects get assembled and re-assembled, and in particular to think about the presence of negative expectation in the everyday labour of research. Nonetheless, by and large, when we are talking about the sociological import of 'expectations' in the sustenance of scientific projects, we are still usually talking about actors orienting themselves to something they imagine to be basically good or optimal. As Brown and his colleagues describe it – the future in question still tends to be one in which:

gene therapy and nanotechnology will cure disease, cars will drive themselves, pigs hearts will be used for organ transplants, computers will become an even more ubiquitous part of life, the Internet and the Cybercafe will become the venue of choice for our relationships, and so on' (2000: 4).

What we see in the close-up space of neurobiological autism research, however, is a significantly more complex and dispersed terrain of expectation – and one that works through some surprisingly uncertain, uneasy and even quite disappointed views of its own basic project. It is not enough to describe this data as an under-current of knowledgeable scepticism within everyday research – i.e. one running below public expressions of hope. This sense of disappointed uncertainty was too present, and too much a feature of my interviews with autism neuroscientists. My argument now is that the on-going generation and sustenance of autism research is actually much more

thickly entangled in a dynamic and ambivalent relationship between languages of uncertainty and discourses of hope (Silverman, 2012: 159-160).

The trouble with brain-imaging

Here is another post-doctoral autism researcher, who was contributing to several major brain-imaging studies of autism – but who, having come to brain-imaging from biology, was also keen to express her early disappointments in this field. 'When you know how the brain works,' she said, 'as a biologist,'

so you know what makes brain activity, which is connection between neurons, and it matters with which part of the brain you're connected, and how fast you get there, and how much information you converge...um, the only thing you get from brain imaging is 'this part of the brain is activated at a particular time.' It tells you very little about the neural mechanism, and how things get connected to each other.

Here, the interviewee shifts from a basic concern with the distance between brain activity and some measurable vascular response, to a more specific uncertainty about the solidity of the relationship between the kind of data generated by brain-imaging measures, and, in general, 'how the brain works.' I want to draw attention, in particular, to the ways that some important normative divisions are being constructed here — between brain-imaging and biology, on the one hand, and even between brain-imaging and brain *science*, on the other. A senior molecular biologist of autism said something very similar, but she embedded her qualms, not so much in terms of the way that connections were being elided, but in the degree of fineness achievable from brain-imaging:

in autism, along with a lot of other conditions, like schizophrenia and even the neurodegenerative conditions, you really need to understand what's going on with gene expression in the brain... The trouble with brainimaging is that it only gets you down to a certain level of fineness in its detection. So you can't tell what's going on at the cellular level, and at the molecular level – which is what you really need to understand if you're going to see what the genes are doing, and what it might be possible to do to improve symptoms that some people with autism have [...] People in brain-imaging talk as if they're looking at pathology in their brain-images. But they're not.

On one level, we could read, here, a standard wet-lab biologist's unease about over-interpretation of the brain image, and some disappointment about its eminence in the field: 'this tremendous emphasis on imaging,' she said later, '[...] has led people to think that everything's virtual these days when, actually, it only gets you a certain way, that virtual reality.' But it is also interesting that the focus of her unease is not an over-interpreting public discourse; her worry is about the limitation of a brain-imaging study of something like autism in the first place.

This sense of limit, which was one of the most consistent sources of unease and disappointment expressed about brain-imaging within my interviews, came out in a few different ways. For some, it was about thinking small: 'in some forms of research,' said a young psychiatrist,

I suppose you might come up with a finding which sort of clearly changes the game. And in brain-imaging in autism, it's rarely that sort of finding.

So, the findings usually sort of move things on in very small steps.

For others, it was about recognising ineffable complexity: 'I don't think it's every going to as simple as "there is this point in the brain that is dysfunctional and this is causing autism," said a PhD student, 'I don't think that's every going to happen. I don't think that's true.' For a more senior investigator, the problem was lack of specificity: 'quite a good pub game,' he said, 'is name a region of the brain that hasn't been associated with autism, by somebody or some paper. It's virtually impossible.' Of course, these are not suggestions that the neuroscience of autism is intrinsically bad or misguided. But there is nonetheless a subtle but consistent sense, here, in which the neuroscience of autism is described as limited small-scale, dispersed, and (so far, at least) not very specific. Whatever hopes had been attached to their research, these scientists also expressed some quite consistently low expectations for the neuroscience of autism. None of them thought that this meant neuroimaging research shouldn't be done (and several went on to talk about the move to 'connectivity,' or some other new paradigm), but I was nonetheless struck by the way in which the neuroscience of autism was consistently self-constructed through an idiom of uncertainty, one that emphasised the biases, the difficulties, and the partial truths.

It is important to note that these claims are not just aberrations or counter-examples of a broader structure of hope, nor are they the predictable *post-hoc* sentiments of people whose research hasn't worked out. Low expectations neither correlate with disappointed careers in my sample, nor are they particularly found among the junior and the put-upon: all of the people just quoted were visibly 'succeeding' in their careers by any reasonable measure. My argument is not that I have found neuroscientists who are unhappy or drifting, or who find themselves inadequate. Nor have I found a cohort of comfortable field-leaders, whose longestablished sinecures give free rein to their doubts. I am trying to show, instead, how

autism research is traced through registers of low expectation as well as structures of 'promissory hope.' In particular, autism neuroscience is narrated by its own practitioners within a register of distinct unease and uncertainty about how a neuroscience of autism might actually come about, and what it would look like if it did – as much as it is structured by a sense of expectation for the therapeutic and diagnostic hopes that neurobiological research may eventually realise.

Structured ambivalence

What I have found, then, is not only a sense of hope, but a much more ambivalent attitude to the future of autism neuroscience. My argument is that this may not be incidental to autism – and that in fact a sense of 'structured ambivalence,' or a discursive register that works through a dynamic of both hope and disappointment, can be interpreted via the complex and shifting zone of autism research, care and practice that I described at the beginning. This is a zone that may be less defined by the 'success' or 'failure' of research that takes place within it, but is instead marked by both the things that researchers simply 'don't know' about autism (Murray, 2012), and, nonetheless, claims upon autism's biological presence and essence (Ortega and Choudhury, 2011) – a zone in which, for example, the emergence of an ever-tighter institutional complex around the diagnosis (Eyal et al, 2010) has co-evolved with an increasingly 'fractionable' and dispersed view from psychology and psychiatry (Happé and Ronald, 2008; Anney et al., 2012).

Autism neuroscience thus does not move towards a clearly imagined future, but neither does it simply stop in its tracks: variously firm and tentative neurobiological markers continue to be both researched and proposed, even if, as yet, none of them have caught on (Ecker *et al.*, 2010; Spencer *et al.*, 2011). Neurobiological autism

research thus does not progress, even in its own self-narration, in an obviously linear fashion. Instead, it works more delicately through the zone of ambiguity and presence that surrounds the biological and social hinterland of autism. As I described in the first section, the modest outcomes of brain-imaging, and the expectations that can be attached to those outcomes, have to be set alongside a whole range of other actors, institutions and literatures variously committed to the indelibility of autistic presence. Within such a zone, intellectual work that might otherwise be carried along by a straightforward discourse of neurobiological reduction needs to find a more complex language. In particular, my data shows how a 'vision' of autism's neurobiological future, if it is to make sense in the present, needs to have something more intricate to draw upon, than those phrases supplied by the strait-laced semantics of hope: to persevere within a zone of both ambiguity and presence, autism neuroscientists must learn to speak the languages of uncertainty, unease, and disappointment too. And while I do not claim that the careful and structured ambivalence that results is unique to autism research – I do locate the degree to which it is forefronted in this space precisely with the kinds of uncertain and complex biosocial repertoires that have formed around autism research, and that have become entangled with autism's emerging possibilities for complex biological and social claims.

A final set of examples to demonstrate this: perhaps most damningly for a practice that lives or dies on its sense of efficacy, there were also suggestions that the neuroscience of autism would only ever go over ground already well-trodden by other experimental psychologies. 'To me,' said one lecturer in cognitive psychology, 'it kind of adds a layer of description...

this is a very simple example, but say we're talking about face-processing and I say that children behaviourally have difficulties processing faces.

And you can do tests to show this. And then, at the neural level, they show less activity in the fusiform face area for faces. To me, that kind of is just another level of description. It doesn't explain anything.

In my reading of her remarks, this lecturer is quite deliberately trying to enact a firm division between cognitive-psychological and neuroscientific studies of autism, positioning them as different (even competing) areas in which to seek the most richly explanatory substrate of a given mental state – and she is arguing that the actual contribution of neuroscience is unclear. This expresses another element of this general ambivalence, which is that neuroscientists of autism have been scanning brains for some time now, and yet it's not clear that the field has dramatically moved forward in that period. 'I think looking at the brain is useful in some respects,' said a young postdoc echoing this view 'but, um, I mean I am always saying that I think a lot of sort of neuroscientific work, especially in terms of fMRI or stuff like that, is a process of re-describing what we know already.' Or as another lecturer put it:

I did see a talk here recently on - it was called 'the neuroimaging of adhd' and that was what it was. And of course functional neuroimaging by itself is meaningless. Because it is just lighting up pictures.'

It seems to me that what these researchers are articulating, when they say things like 'it's meaningless' or 'it doesn't explain anything' is a basic anxiety that there has been a disciplinary over-investment in a disappointing brain-science — and that, in fact, attaching categories like autism to localised neurological signatures might not add a great deal to the field. This is where I think we reach something close to the opposite of a promissory vision, and we begin to see the draw of a structured ambivalence. 'I think I worry that there's so much emphasis on brains,' said a young lecturer: 'I think

we need to know what's going on at the neural level – um, but we also need to know how kids with autism think, and feel, and view the world.'

My argument is that the consistency of these kinds of claims, in which this specific group of people, whose professional identity is wholly or partly invested in some practice of doing brain-imaging studies of autism, but who nonetheless frequently position brain-imaging as either partial, or flawed, or slow, or misleading, or invalid, or maybe just inappropriate to studying things like autism in the first place – that the preponderance of these accounts finally adds up to something noteworthy. The thick patina of low expectation that seems, somehow, inseparable from so many of these neuropsychologists' and neuropsychiatrists' accounts of their daily practice requires an additional kind of explanation for how these researchers orient themselves to the future. My emphasis has been on the location of autism research within a strange zone of biological productivity and opacity, as well as political contest and scientific uncertainty. I argue that this zone has necessitated a different, and much more ambivalent, kind of discursive and imaginary strategy than one of positive expectation alone. In particular, at least within the space of autism neuroscience, it has required researchers to learn to narrate their research in dynamic registers, in which hopes and promises have become tempered by disappointments, anxieties and uncertainties. As well as bringing a new perspective to the 'sociology of expectations,' and to studies of neurobiological research, this is also a powerful example of the kinds of novel languages and repertories that have formed around autism research, and of the strange spaces within which ordinary autism scientists have to locate themselves. This is further evidence of the 'intermediate terrain' within which practices of research, care and activism have taken shape around autism – and of the importance of

understanding autism in thinking about the configurations and reconfigurations that particularly mark the contemporary biosciences.

Conclusion

The 'sociology of expectations' has been a potent frame for thinking about the ways that scientific projects are both assembled and sustained, and it has not been my goal to fundamentally disagree with this literature. What I have tried to show, instead, is that there are technoscientific spaces that seem to proceed also within more strange and dynamic registers of hope and disappointment; my major point has been, therefore, that a subterranean discourse of low expectation, as well as the 'structured ambivalence' that admits of it, may need to be brought more prominently into discussions of scientific futures. And these low expectations are present at all levels, and all career-stages, within the sample of autism neuroscientists that I spoke to. Seeing the co-presence of both registers so present, and dispersed, I argued that working through a register of ambivalence allows neuroscientists to enact and sustain projects that have an in-built ambiguity or uncertainty. In the case of autism research, I showed how that ambiguity is particularly manifest in the intermediate zone of, on the one hand, autism's social and clinical presence, and, on the other, its neurobiological and genetic uncertainty – a complex, entangled space that has allowed a variety of actor to make a series of novel links between shifting biosocial categories. I argued that neurobiological researchers thus need to work through and across a more dynamic, ambivalent terrain of expectation – one that can gather together both promises and disappointments. Finally, while this special issue has drawn attention to the salient gap around autism research particularly, it may be that similar dynamics of hope and disappointment play a similar role in other neuropsychiatric and

neurobiological spaces. If autism has had a particularly awkward terrain of emergence, it is not the only diagnostic category where presence and biology are poorly matched (Kapur *et al.*, 2012). Autism research is a particularly rich site for social scientists of health and illness – but whether autism neuroscience is unusual in this particular regard, or simply pioneering, remains to be seen.

Bibliography

American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders DSM-IV-TR 4*. Washington DC: Amer Psychiatric Pub.

American Psychiatric Association. (2011). DSM-5 Development: A 09 Autism Spectrum Disorder

http://www.dsm5.org/ProposedRevisions/Pages/proposedrevision.aspx?rid=94> [Accessed April 28, 2012].

Andreasen, N.C. (2001). Brave new brain: conquering mental illness in the era of the genome, Oxford: OUP

Anney, R., et al. (2012). Individual common variants exert weak effects on the risk for autism spectrum disorders, Human Molecular Genetics advance online publication, July 29, 2012; doi: 10.1093/hmg/dds30

Bailey, A. et al. (1995). Autism as a strongly genetic disorder: evidence from a British twin study. *Psychological Medicine*, 25(1), 63–77.

Baron-Cohen, S. et al. (2009). Prevalence of autism-spectrum conditions: UK school-based population study. *British Journal of Psychology*, 194, 500–509.

Borup, M., et al. (2006). The sociology of expectations in science and technology. *Technology Analysis & Strategic Management*, 18(3-4), 285–298.

Brown, N. and Michael, M. (2003). A Sociology of Expectations: Retrospecting Prospects and Prospecting Retrospects. *Technology Analysis & Strategic Management*, 15(1), 3–18.

Brown, N., Rappert, B. and Webster, A. (2000). Introducing contested futures: from looking into the future to looking at the future. In: N. Brown, B. Rappert, and A. Webster (Eds), *Contested futures: a sociology of prospective techno-science*. Aldershot: Ashgate.

Bumiller, K. (2008). Quirky Citizens: Autism, Gender, and Reimagining Disability, *Signs*, 33(4), 967–991.

CDC. (2012). CDC Features - Why Are Autism Spectrum Disorders Increasing. http://www.cdc.gov/Features/AutismPrevalence/ >[Accessed July 13, 2012].

Choudhury, S., Nagel, S.K. and Slaby, J. (2009). Critical neuroscience: linking neuroscience and society through critical practice. *BioSocieties* 4, 61–77.

Choudhury, S. and Slaby, J. (2012). Critical neuroscience - between lifeworld and laborator. In: J. Slaby and S. Choudhard (Eds.), *Critical Neuroscience: A Handbook of the Social and Cultural Contexts of Neuroscience*. London: WileyBlackwell.

Dumit, J. (2004). *Picturing personhood: brain scans and biomedical identity*, Princeto: Princeton University Press.

Ecker, C., et al. (2010). Describing the Brain in Autism in Five Dimensions-Magnetic Resonance Imaging-Assisted Diagnosis of Autism Spectrum Disorder
Using a Multiparameter Classification Approach', *Journal of Neuroscience*, 30(32), 10612–10623.

Eyal, G. et al. (2011). *The autism matrix: the social origins of the autism epidemic*, London: Polity.

Feinstein, A. (2010). A History of Autism: Conversations with the Pioneers. London: WileyBlackwell.

Geschwind, D.H. and Levitt, P. (2007). Autism spectrum disorders: developmental disconnection syndromes. *Current Opinion in Neurobiology*, 17(1), 103–111.

Great Britain. (2009) Autism Act 2009 (c.15). London: The Stationary Office.

Gupta, A.R. and State, M.W. (2007). Recent advances in the genetics of autism. *Biological Psychiatry*, 61(4), 429–437.

Happe, F. and Frith, U. (eds.) (2010) Autism and Talent. Oxford: OUP.

Happé, F. and Ronald, A. (2008). The 'Fractionable Autism Triad': A Review of Evidence from Behavioural, Genetic, Cognitive and Neural Research.

Neuropsychology Review, 18(4), 287–304.

Happé, F., Ronald, A. and Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience*, 9(10), 1218–1220.

Hyman, S.E. (2008). A glimmer of light for neuropsychiatric disorders. *Nature* 455(7215), 890–893.

Kapur, S., Phillips, A.G. and Insel, T.R. (2012). Why has it taken so long for biological psychiatry to develop clinical tests and what to do about it? Molecular Psychiatry advance online publication, August 7, 2012, doi: 10.1038/mp.2012.105

Kitzinger, J. (2008). Questioning Hype, Rescuing Hope? The Hwang Stem Cell Scandal and the Reassertion of Hopeful Horizons. *Science as Culture*, 17(4), 417–434.

Knapp, M. (2012), 'Professor Martin Knapp: Autism Costs', *LSE Health and Social Care*.

<< http://blogs.lse.ac.uk/healthandsocialcare/2012/04/09/professor-martin-knapp-autism-costs/>> [Accessed August 15, 2012].

Knapp, M., Romeo, R. and Beecham, J. (2009). Economic Cost of Autism in the UK. *Autism*, 13(3), 317–336.

van Lente, H. (2000). Forceful futures: from promise to requirement. In: N. Brown, B. Rappert, and A. Webster (Eds), *Contested futures: a sociology of prospective technoscience*. Aldershot: Ashgate.

van Lente, H. and Rip, A. (1998). Expectations in technological developments: an example of prospective structures to be filled by agency. In: C. Disco and B. ven der Meulen (Eds.), *Getting New Technologies Together. Studies in Making Sociotechnical Order*. Berlin: De Gruyter.

Lord, C. et al. (2011). A Multisite Study of the Clinical Diagnosis of Different Autism Spectrum Disorders. *Archives of General Psychiatry*, 69(3), 306–313.

Martin, E. (2004). Talking back to neuro-reductionism. In: H. Thomas and J Ahmed (Eds.) *Cultural bodies: ethnography and theory*, 190-211. Oxford: Blackwell.

Moreira, T. and Palladino, P. (2005). Between truth and hope: on Parkinson's disease, neurotransplantation and the production of the 'self'. *History of the Human Sciences*, 18(3), 55–82.

Murray, S. (2011). Autism. London: Routledge.

- (2008) Representing Autism: Culture, Narrative, Fascination. Liverpool: Liverpool University Press.

Nature (2010). A decade for psychiatric disorders. Nature, 463(7277), 9.

Navon, D. (2011). Genomic Designation: How Genetics Can Delineate New, Phenotypically Diffuse Medical Categories. *Social Studies of Science*, 41(2), 203-226

Ortega, F. (2009). The Cerebral Subject and the Challenge of Neurodiversity. *BioSocieties*, 4, 425–445.

Ortega, F. and Choudhury, S. (2011). Wired up differently: autism, adolescence and the politics of neurological identities. *Subjectivity*, 4(3), 323–345.

Ortega, F. and Vidal, F. (eds.) (2010). *Neurocultures: Glimpses into an Expanding Universe*. Berlin: Peter Lang.

Pickersgill, M. (2011). Promising' therapies: neuroscience, clinical practice, and the treatment of psychopathy. *Sociology of Health & Illness*, 33(3), 448–464.

Raff, M. (2009). New Routes into the Human Brain', Cell, 139(7), 1209–1211.

Rosengarten, M. and Michael, M. (2009). The performative function of expectations in translating treatment to prevention: The case of HIV pre-exposure prophylaxis, or PrEP. *Social Science & Medicine*, 69(7), 1049–1055.

Schreibman, L. (2005). *The Science and Fiction of Autism*. Boston: Harvard University Press.

Silverman, C. (2011). *Understanding Autism: Parents, Doctors, and the History of a Disorder*. Princeton: Princeton University Press.

Singh, I. and Rose, N. (2009). Biomarkers in psychiatry. *Nature*, 460, 202–207.

Solomon, A. (2008). 'The Autism Rights Movement', *New York Magazine*. <http://nymag.com/news/features/47225> [Accessed July 19, 2012].

Spencer, M.D. et. Al. (2011). A novel functional brain imaging endophenotype of autism: the neural response to facial expression of emotion. *Translational Psychiatry*, 1, e19.

Vrecko, S. (2010). Birth of a brain disease: science, the state and addiction neuropolitics. *History of the Human Sciences*, 23(4), 52–67.

Vul, E., et al. (2009). Puzzlingly high correlations in fMRI studies of emotion, personality, and social cognition. *Perspectives on Psychological Science*, 4(3), 274-290.

Yates, D. (2012). Neurogenetics: Unravelling the genetics of autism. *Nature Reviews Neuroscience*, 13(6), 359–359.