# From the profound to the mundane: Questionnaires as emerging technologies in autism genetics

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## Abstract

It is widely argued that the final decades of the twentieth century saw a fundamental change, marked by terms such as biomedicalization and geneticization, within the biomedical sciences. What unites these concepts is the assertion that a vast array of emerging technologies—in genomics, bioengineering, information technology, and so forth—are transforming understandings of disease, diagnosis, therapeutics, and working practices. While clearly important, these analyses have been accused of perpetuating theoretical trends that attribute primacy to the new over the old, discontinuity over continuity, and the laboratory over the field. In this paper I show that in the case of autism the effects of genomic technologies can only be understood by simultaneously examining the role of questionnaires. Due to shortcomings in clinical diagnoses, genomic analyses could only progress once questionnaires had been developed to address a "reverse salient" within the "technological system." Furthermore, I argue that questionnaires such as the Autism Quotient have a significance that surpasses the genomic classifications they were designed to undergird. I argue that to neglect the role of mundane technologies such as questionnaires in contemporary biomedicine is to miss complexity, bifurcate old and new, and do a disservice to innovation.

**Introduction**

It is widely argued that the final decades of the twentieth century saw something of a paradigm shift in the biomedical sciences—a biomedicalization and molecularization that ushered in a new "regime of truth" (Clarke et al. 2003: 163) or "politics of life" (Rose 2001; Rose 2007). This new vision claimed that technological advances would facilitate a comprehension of life's code, from the genome up, and lead to significant new understandings of both health and illness. And while the results of the Human Genome Project gave pause for thought, the story goes, this process continues more or less unabated.

In focusing upon autism here, I am not contesting the described dominance of biomedicine: In the UK, the majority of research funding goes on understanding the biology of autism, a finding mirrored—albeit to a lesser extent—in the United States (Pellicano et al. 2013: 22; Singh et al. 2009). Similarly, the majority of both scientists (Decoteau & Underman 2015) and parents (Silverman 2008; Singh 2014) appear to understand autism as a genetic, often heritable condition. These findings alone lead to the conclusion that autism has undergone a process of "geneticization" (Bumiller 2009; Navon & Eyal 2014; Navon & Eyal 2016), at least in the "stripped down" sense offered by Hedgecoe (2001: 876) and quite possibly in the broader sense articulated by Lippman (Lippman 1992).[1] Nonetheless, I am uncomfortable with the above descriptions in relation to autism. Revolving as they do around novel and emerging biotechnologies, the terms are suggestive of a sharp break, or epistemic shift, away from "clinical" gazes and "traditional" technologies. Accordingly, they risk perpetuating trends in science and technology studies (STS) and medical sociology that have long been critiqued for attributing a primacy to the new over the old, discontinuity over continuity, and the laboratory over the field (Edgerton 2008; Kerr 2004); "blinded by novelty," as Raman and Tutton succinctly put it (Raman & Tutton 2010: 729).

Here, then, I seek to trouble existing accounts of emerging biotechnology in autism, a condition that in many senses typifies and thus speaks to broader processes of geneticization. Drawing upon a wide range of published sources, I argue that molecular genetics and genomics do indeed play a crucial role in

[1] Hedgecoe's "stripped down" definition suggests "that in medicine, geneticization takes place when a condition is linked to a specific stretch of DNA" (Hedgecoe 2001: 876). Lippman is not restricted to changes "in medicine" and considers, for instance, changes in the ontology of the self. As Weiner's work has repeatedly shown (e.g. Weiner et al., 2017), the sociological reality of these two processes is largely separable.

contemporary understandings of autism. However, this role can only be understood by considering a significant number of mundane "classical" methods that are diffracted through emerging biotechnologies. In the case of autism, the classical methods of greatest note are a number of questionnaires—the Autism Quotient, the Broader Autism Phenotype Questionnaire, and the Social Responsiveness Scale, amongst others—created at the turn of the twenty-first century in order to address a "reverse salient" (Hughes 1987) in large technological systems oriented towards a genomic understanding of autism. Furthermore, I argue that the cultural and scientific significance of these questionnaires surpasses the genomic classification they were devised to undergird; by virtue of their simplicity and mobility these questionnaires have been utilized in a range of contexts—both inside and outside of scientific institutions—with a wide range of consequences.

That the social science literature focuses upon emerging genomic technologies, to the exclusion of the pen and paper innovations examined here, ensures that theses considering the geneticization of autism simultaneously over- and under-play the importance of genetics. They *over*play the role of emerging technologies by failing to grasp that changes are better understood as part of larger system that cannot be radically disconnected from the past. They concurrently *under*play the role of these biotechnologies by failing to see their influence in diverse, mundane settings often far removed from the site of origin. In making this argument, I do not deny the importance of genetics or genomics in general or in relation to autism. Rather, I suggest that arguments that claim that autism has been straightforwardly biologized, medicalized, or geneticized miss a great deal of complexity and bifurcate old and new concepts and technologies, doing a disservice to innovation (Edgerton 2008: xiv) and failing to see the influence of this technological system in diverse settings that are often far removed from genetically oriented clinical or laboratory settings.

**Autism and genetics**

It would be wrong to say that a genetic autism is an axiom as has been argued, for example, to be the case with schizophrenia (Hedgecoe 2001: 880). From its discovery in the 1940s through until at least the 1960s autism was primarily understood as an acquired condition caused by maternal deprivation (Evans 2013: 9; Silverman 2012: 61-92) and numerous groups continue to dispute a genetic ontology (Decoteau & Underman 2015; Hobson-West 2007). Nonetheless, perhaps the most striking thing about autism's

"geneticization" is just how typical the process has been. Since the 1960s autism has been described in genetic terms (Silverman 2012: 144; Singh 2016: 86) and, as has been widely discussed within the social science literature (Evans 2013; Eyal et al. 2010: 14; Feinstein 2010: 140; Silberman 2015: 346; Silverman 2012: 146; Singh 2016: 86), genetic research has played an increasingly important role since the 1970s when twin studies, most notably that conducted by Susan Folstein and Michael Rutter in 1977, showed that monozygotic twins have incredibly high levels of concordance for autism symptomology.

It seems unlikely that any scientist ever thought it would be quite as simple as locating an "autism gene," for researchers from various disciplines had been proposing a genetically heterogeneous condition since at least the late 1970s (e.g., Freeman 1977: 143). Nonetheless, it was still hoped that the insights from the Human Genome Project would locate the genetic underpinnings of autism. However, and as Rose has phrased it more generally, this vision of the grail "proved to be as ephemeral as most such visions" (Rose 2007: 46) with a widespread failure to replicate findings (see Vorstman et al. (2017) for an overview of contemporary autism genetics). It has been widely argued that, following these failures, autism researchers changed tack and began to turn away from genetics and towards genomics. As Singh has phrased it, instead of operating under "the assumption that autism is a result of a major heritable gene," this "emergent way of scientifically viewing and practicing autism implicates hundreds of genes interacting with one another at the molecular level" (Singh 2016: 83). The attempt to explicate autism in genomic terms can be understood as a "common system goal" (Hughes 1987: 51) for a great deal of contemporary research into the condition and, as we know, autism is pretty well typical in this regard (Mitchell & Waldby 2010).

This shift from genetics to genomics has, again, been understood by some as a paradigmatic or epistemic shift; evidence of an emergent genomic style of thought or genomic gaze (Bliss 2015; Rose & Abi-Rached 2013: 44; Singh 2016). It is argued that this shift has profound implications for autism, with new "trading zones" emerging that connect previously diverse groups of patients (Navon & Eyal 2014) and facilitate diagnostic expansion (Navon & Eyal 2016). New and emerging biotechnologies are foregrounded in these descriptions— "Technologies such as DNA and chromosomal microarrays, next generation sequencing, and computer bioinformatics have become essential tools..." (Singh 2016: 82)—binding together epistemic shifts and novel technologies.

Again, these processes are at once specific to autism and typical of geneticization theses. It is perhaps unsurprising to note, therefore, that the primacy afforded to emerging biotechnology in relation to autism is also found within the broader theoretical literature. Clarke's pioneering work on biomedicalization—a reference point for much of the autism literature that bears similar traits (e.g. Bumiller 2009; Singh 2016)––for example states that:

> Extensive transformations are produced through new diagnostics, treatments, and procedures from bioengineering, genomics, proteomics, new computer-based visualization technologies, computer-assisted drug developments, evidence-based medicine, telemedicine/telehealth, and so on. (Clarke et al. 2003: 162)

Nikolas Rose, a similarly smoothed touchstone, claims that medicine "…itself has been transformed. It has become technomedicine, highly dependent upon sophisticated diagnostic and therapeutic equipment" (Rose 2007: 11). What is missed in this foregrounding of biotechnology and transformation, however, is the fact that these "high tech" advances are inextricably bound with technologies that are far more mundane and, in many cases, have a much longer history.

**Accounting for the mundane**

Historians of technology remind us that we must not be too hasty to put boundaries around the edges of what constitutes an "emerging" technological system (Callon 1981; Hughes 1987) and that attempting to understand the influence of emerging technologies without consideration of their mundane and developed kin is likely to give a distorted image (Edgerton 2008). Perhaps to a greater extent than allied fields (Timmermans & Berg 2003: 104) work within STS has emphasized the importance of mundane technologies within society (e.g. Latour 1988; Michael 2000; Pinch 2010; Woolgar & Neyland 2013). Nonetheless, and as Michael has noted (2003), analyses rarely place mundane and "exotic" technologies into conversation with each other.

Michael (2003) hypothesizes that this lack of conversation between analyses of "mundane" and "exotic" technologies is as much about academic division of labor as it is the state of the world: Scholars interested in "sober being" tend to focus upon mundane technologies, while those interested in "spectacular becoming" orient towards the exotic (Michael 2003: 128). An erroneous suggestion implicit in this divide,

Michael suggests, is that mundane technologies like Latour's door closers (1988) are involved in the *reproduction* of existing social worlds, while exotic emerging technologies—like the biotechnologies examined here—are involved in the *production* of new worlds (Michael 2003).

The tight binding of the exotic and the productive, I would suggest, is evident in much of the literature discussed in previous sections. Despite this, we know that both old and mundane technologies play hugely significant roles within both medical (Berg 1996; Berg 1997) and psychiatric (Swallow 2015; Wilson 2014) settings. Indeed, we also know that within biomedical settings emerging and mundane technologies actively co-constitute each other within large technological systems (Timmermans & Berg 2003: 104).

The inseparability of emerging and mundane technology, for example, is evident in DeCODE Genetics' project in Iceland, one of the most written about enterprises of the genomic era (e.g. Fortun 2008; Pálsson & Rabinow 1999). Although rarely emphasized, Ian Hacking argues that what made Iceland uniquely attractive for a population mapping project like DeCODE's was neither the genetically homogenous nature of the population nor that population's stability, both of which were important but hardly unique. Instead it was the nation's literacy and the fact that it "had never had a mass destruction of [written] records... genealogies back to 1708 are reliable," which made it so appealing (Hacking 2007: 97). Understanding the *census*, the *questionnaire*, in other words, is crucial to understanding why Iceland became a hub of biotechnological research. Indeed, what the literature on biobanking shows more generally (Mitchell & Waldby 2010), is that if information gathered through questionnaires, for example, does not exist already, it must be gathered alongside biological material, with new instruments created if necessary. The production of novel mundane technologies, that is, may be crucial to biotechnological enterprise.

**Endophenotypes and the need for novel diagnostics**

In order to grasp the importance of questionnaires in contemporary understandings of autism it is crucial to recognize that studies in genomics are frequently based not upon clinical phenotypes but, instead, *endo*phenotypes (Losh & Piven 2007: 105). Endophenotypes are so called "intermediate phenotypes" that are:

> ...a heritable phenotypic feature that is closely related to a disorder but represents a more narrow or simple component than the disorder itself. An endophenotype should be observed in first-

> degree relatives more frequently than in the general population and might be quantitative rather than binary. (Geschwind 2011: 409)

Autism endophenotypes thus differ from the clinical phenotype in important ways. The clinical autism phenotype consists of "persistent deficits in social communication and social interaction," and "restricted, repetitive patterns of behavior, interests, or activities" (American Psychiatric Association 2013: 50). Although framed as a dyad in DSM-5, this phenotype is historically referred to as the "autism triad"; it is the co-occurrence of the three symptom clusters (in social functioning, communication and restricted interests) that demonstrates a clinical phenotype. An endophenotype, however, may apply to just one of these domains (e.g. symptoms related to social functioning but not communication or restricted interests). Furthermore, behaviors associated with the endophenotype may be less pronounced than those associated with the clinical phenotype. Thus, an endophenotype relating to impaired communication may present itself in a dislike of social chitchat (Baron-Cohen et al. 2001) rather than a clinical "mindblindness" (Baron-Cohen 1995).[2] In the case of autism, those with endophenotypes are often said to exhibit the "broader autism phenotype."

There are two sound reasons for researchers working in genomics to focus upon endophenotypes, both relating to the issue of statistical power. First, core assumptions of genomic science are that autism is both heritable and arises as a result of multiple genes interacting. If this is the case then family members below the clinical cut-off for autism will both share some susceptibility genes for autism and present lesser symptoms of the sort described above. It would thus be an error to include family members in an undifferentiated non-clinical control group, because family members who "are just below [clinical] cutoff may, in fact, share several genetic risk factors but would be classified as unaffected, so some information is lost," with the result that the effects of these genes are obscured (Duvall et al. 2007: 658-659). Second, because it is believed that genetic studies will reveal numerous genetic sub-groups and that "common autism gene variants are likely to be of weak effect," genomic analyses will "typically require very large sample sizes in order to have sufficient power" to detect candidate gene variants (Sucksmith et al. 2011: 382). In practical

[2] There are a number of assumptions built into this model, for example that dislike of social chitchat and an inability to understand others thoughts and intentions (mindblindness) differ quantitatively rather than qualitatively.

terms, therefore, being able to include individuals who do not have clinically diagnosable autism, but who do share autism gene variants, in a study design is exceptionally useful.

It is these two important points—the need to make significant use of the non-clinical population and the requirement that very large sample sizes are used—that has necessitated the turn to endophenotypes. MSSNG, "..a groundbreaking collaboration between Google and Autism Speaks [which seeks] to create the world's largest genomic database on autism" (Autism Speaks,n.d.) is, for instance, archetypical of contemporary endophenotypic studies: A collection of 10,000 DNA samples representing trillions of data points from both individuals with a diagnosis and their families. MSSNG is far from being alone in seeking a model of this sort (Silverman 2012: 157-160; Singh 2016: 46-53).

Despite utilizing cutting edge genomic and computer technologies, however, studies like MSSNG remain absolutely dependent upon behavioral observations; a biomarker must be correlated against a behavior in order for its effect to become apparent (Abend 2017). Langlitz has explored this issue in relation to neuroscientific investigations of consciousness:

> The investigation of neural correlates of consciousness and subjectively experienced mental events... requires that test subjects provide first-person accounts of their experiences. Otherwise, it would be impossible to tell what the measured neural correlates were correlates of. (Langlitz 2010: 43, references removed)

The same situation applies in autism genomics: In order to be understood, genotypes must be correlated against behavioral (endo)phenotypes. As an example, Alarcón et al. (2002) explore the underpinnings of social communication by examining correlations between genetic markers and behavioral criteria like "age at first word." Without an observable, behavioral measure of social communication (such as age at first word) the effect of particular gene variants cannot be interpreted. To this end, studies like MSSNG—where truly vast numbers of people are donating data and a good number of those people do not exhibit a clinical phenotype—quickly encounter a problem with existing diagnostic procedures used to gather behavioral data, and they do so for at least three reasons.

First, clinical examinations take too long, and are too expensive, to be practical with extremely large samples. For example, the Autism Diagnosis Observation Schedule (Lord et al. 1989; Lord et al. 2000), or ADOS,

is often described as the "gold standard" diagnostic instrument within both clinical and research settings (Fombonne 2009: 592; Norbury & Sparks 2013: 7) and would be an obvious tool to gather the behavioral data required to interpret genomic analyses. An ADOS session takes around 40 minutes to complete and requires two highly trained observers who attend and re-watch and discuss diagnostic sessions (Hollin & Pilnick 2018). Such a process is simply too time- and resource-intensive for many of the studies imagined within genomics, which require huge sample sizes.

Second, endophenotypes are assumed to be both quantifiable (i.e., exist in lesser variants) and apply to a narrow sub-component of the clinical phenotype (e.g. social communication but not social functioning or restricted interests). Thus, and as noted above, while an individual with the clinical autism phenotype may demonstrate both mindblindness (an inability to determine others' intentions) and restricted interests, an individual on the endophenotype may simply dislike social chitchat. Thus, diagnostic tools need to be able to both quantify an individual's "degree of autisticness" and examine the possible existence of diverse sub-groups. Clinical methods such as the ADOS, however, were intended to provide little more than a yes/no qualitative diagnosis. Thus, while some quantification is possible with existing diagnostics (Lord et al. 2001), they are not ideal even when resource intensity is not an issue.[3]

Finally, third, clinical tools like the ADOS are simply not sensitive enough to locate endophenotypes: There are almost certainly "ceiling effects" (Constantino & Todd 2003: 529) in traditional diagnostics whereby many exhibiting an endophenotype would simply pass the test and score zero. For example, those who simply dislike social chitchat would, over the course of the ADOS, almost certainly still establish enough rapport with the examiner that they would be deemed to have no communication impairment. This would lead to individuals exhibiting endophenotypes being labeled "unaffected" and the effect of genes obscured.

For these three reasons, the turn to endophenotypes within a system oriented towards the goal of understanding autism in genomic terms rendered existing diagnostic techniques problematic. Importantly, these problems are both technical—the need for instruments with increased sensitivity and the ability to

[3] While it will always be time-intensive to collect data via a tool such as the ADOS, resources may be less of an issue, for example, because data is being collated from numerous collection sites.

provide quantitative measures—and economic; the huge numbers of people imagined necessary for genomic analyses necessitating a need for instruments to reveal phenotypes at a greatly reduced cost.

**Genomic science: A technological system with a reverse salient**

And this is where we start to move away from a narrow focus upon chromosomal microarrays and computing power. For while there is undoubtedly truth in assertions that these novel pieces of machinery are essential for ongoing genomics research, what the above discussion makes clear is that these tools could not be used effectively without additional, mundane, innovations. The story of autism's contemporary configurations can only be told if we include technologies that were intended to overcome the aforementioned limitations of existing diagnostics and designed to be cheap, easy, and quantitative. These technologies, in short, are questionnaires and surveys.

We can understand the importance of questionnaires within contemporary genomics by utilizing the work of historian of technology Thomas Hughes (e.g. Hughes 1987). Hughes' work details processes of change within "large technological systems" (LTS), a concept that has much in common with Michel Callon's technoscientific "actor-worlds" (Callon 1981: 23).[4] Indeed, by working through the cases examined by Hughes and Callon—Edison's successful "electrification in Western society" in the case of the former (Hughes 1983) and Electricitié de France's (EDF) failed promotion of the véhicule électrique (VEL) in the case of the latter (Callon 1981)—the core features of LTS can be discerned.

First, LTS must be understood broadly and taken to include both material and semiotic features (Hughes 1987: 51). The material-discursive nature of technological systems is made clear in both the case of Edison wherein the network included "physical artefacts, mines, manufacturing firms, utility companies, academic research and development laboratories, and investment banks" (Hughes 1986: 287) and in the case of the VEL where consumers, social movements, ministries, accumulators, fuel cells, electrodes, electrons,

[4] Sovacool and colleagues identify a difference in "focus," rather than any overarching claim, to be the distinguishing difference between scholars who have followed an LTS approach and those like Callon embedded in Actor Network Theory (2018: 7). Here I emphasize the similarities and treat them both as examples of "technology-in-practice" (Timmermans & Berg 2003: 103). See Hughes (1986: 287-290) for a discussion on the points of similarity between "networks" and "systems" and Sovacool & Hess (2017) for a useful overview of frameworks detailing technological change and infrastructure.

catalysts, and electrolytes are all crucial (Callon 1981: 22). These heterogeneous elements form a single LTS that cuts across analytic categories such as scientific, technical, legal, economic, social, and political.

Second, heterogeneous elements must be understood as being co-constituted *within* a system, "designed to interact harmoniously with the characteristics of the others" (Hughes 1986: 288). Callon makes this point clearly, stating that once "…an actor-world comes into being, it does not draw entities from previously established stock. It is not constituted in the way a shopping cart is filled" (1981: 24). The example of car manufacturer Renault, an imagined element within the LTS oriented towards the production of the VEL, makes this clear. At the time of EDF's intervention, Renault was "a powerful company that seeks to be the largest European car manufacturer" (Callon 1981: 22). Within the emerging LTS, however, Renault was reduced to little more than "a modest entity that intervenes in the assembly of the VEL" by providing car chassis (Callon 1981: 22-23). "Renault" thus changes character considerably and loses its "categorical integrity" (Hughes 1986: 289): the "Renault" of the LTS oriented towards the VEL is quite different to the "Renault" in previously established stock.

Third, components in an LTS are not only mutually-constitutive but also mutually-dependent. Such dependency ensures that if one component in a system is:

> …removed from a system or if its characteristics change, the other artifacts in the system will alter characteristics accordingly. In an electric light and power system, for instance, a change in resistance, or load, in the system will bring compensatory changes in transmission, distribution, and generation of components. (Hughes 1987: 51)

If compensation cannot be achieved then complete system break down may be experienced (Callon 1981: 23).

Hughes developed the concept of the "reverse salient" in order to better understand responses to system breakdown, lag, or friction:

> A salient is a protrusion in a geometric figure, a line of battle, or an expanding weather front. Reverse salients are components in the system that have fallen behind or are out of phase with the others. (Hughes 1987: 73)

MacKenzie and Wajcman, expanding upon the Hughes' definition, similarly draw attention to the term's military usage:

> The reverse salient is a product of uneven development. It is an area where the growth of technology is seen as lagging, like a military front line which has been pushed forward but where in one particular spot the enemy holds out. Technologists focus inventive effort, like generals focus their forces, on the elimination of such reverse salients; a successful inventor defines the reverse salient as a set of "critical problems" that, when solved, will correct the situation. (MacKenzie and Wajcman 1999: 17)

Given that reverse salients have wide reaching effects, posing a problem for the whole system, it is perhaps unsurprising that, as suggested by MacKenzie and Wajcman, "communities of inventors congregate at reverse salient sites..." (Hughes 1987: 74) attempting to address the situation and allow development to continue.

If, as previously discussed, we consider it a common system goal of contemporary autism research to understand the condition in genomic terms then I suggest that we can readily understand clinical diagnostics as representing a reverse salient within this system. As discussed above, behavioral diagnostics continue to play a crucial role within contemporary bioscience (cf. Abend 2017; Langlitz 2010) and are thus an essential part of the LTS. For both the technical and economic reasons outlined above, however, clinical procedures such as the ADOS represent a significant lag within the system.

As discussed above, Hughes suggests that when such a lag becomes evident within a community we should see a gathering of inventors seeking to address the problem. In the following section I will argue that just such a gathering occurred in the first years of the twenty-first century, with numerous research groups creating questionnaires designed to correct the reverse salient caused by clinical diagnostics. This observation, I suggest, demonstrates the importance of questionnaires to contemporary genomics research, the entanglement of emerging and mundane technologies in contemporary autism science, and the significant continuities between this contemporary system and past understandings.

**Questionnaires: Addressing the reverse salient**

The first decade of the twenty-first century saw numerous questionnaires published that attempted to address the reverse salient in diagnostics detailed above. These questionnaires included the Autism-Spectrum Quotient (AQ; Baron-Cohen et al. 2001), the Broader Autism Phenotype Questionnaire (BAPQ; Hurley et al. 2007), the Social Responsiveness Scale (SRS; Constantino & Gruber 2007), the Children's Communication Checklist (CCC; Bishop et al. 2006), and the Subthreshold Autism Trait Questionnaire (SATQ; Kanne et al. 2012).[5] Scientists well recognized the importance of these questionnaires to ongoing genomic inquiries and instruments were either immediately used as part of genomic investigations or were explicitly positioned as being of utility to such projects. In this section I will detail the core characteristics of these questionnaires and show that they each sought to address the key features of genomic science's reverse salient by addressing issues of affordability, sensitivity, and quantification. As three of the most widely used measures, my focus here is particularly upon the AQ, the BAPQ, and the SRS, although conclusions are applicable more widely.[6]

As noted above, genomic analyses are increasingly understood as requiring very large sample sizes (Abrahams & Geschwind 2008: 350) and yet remain reliant upon behavioral diagnostics. Existing diagnostic technologies that take a lengthy period of time to conduct are costly in terms of time and money, posing problems of affordability. This issue of affordability was an explicit justification for the creation of the scales under consideration here (e.g. Hurley et al. 2007: 1688). In developing the AQ, for example, Baron-Cohen and colleagues note that "[e]xisting instruments, such as the ADI-R (Autism Diagnostic Interview), [and] the ADOS-G (Autism Diagnostic Observation Schedule) are fairly time-consuming to administer..."

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[5] In addition to these questionnaires, Lord et al. (2001) suggested that the ADOS, outlined above, was a suitable instrument for quantification and Dawson et al. (2007) produced the "Broader Phenotype Autism Symptom Scale," or BPASS. Like the ADOS, the BPASS requires extensive observation and interview by trained clinicians. Both of these papers were explicitly targeted at quantifying autism for the purpose of genetic analysis (Dawson et al. 2007: 524; Lord et al. 2001: 36) and can be understood as attempts to address the same reverse salient as detailed above. Nonetheless, there has been a (relative) lack of uptake of these instruments, at least in the context considered here. I suggest this lack of uptake is due to the fact that while the BPASS seeks to address issues of sensitivity and quantification, the continued reliance upon trained clinicians means that economic issues are not addressed and, thus, the reverse salient remains.

[6] The research groups that developed these questionnaires—such as Simon Baron-Cohen's at The University of Cambridge and John Constanino's at The Washington University School of Medicine in St. Louis—frequently were involved in *both* the development of questionnaires and the undertaking of genomic analyses. Thus, as was the case in Hughes' historical analyses, "system builders were no respecters of knowledge categories or professional boundaries" (Hughes 1986: 285). The lack of attention paid to questionnaires is a feature of the social scientific literature on genomics, not the scientific literature itself.

(Baron-Cohen et al. 2001: 6). Constantino and colleagues, discussing the SRS, note the particular problem that lengthy diagnostics cause for large scale projects typical of genomic analyses: "[the] ADI-R takes upwards of two hours to complete, and this has limited its feasibility in clinical settings and in large population-based studies" (Constantino et al 2003: 428).[7]

The construction of questionnaires like the AQ and the SRS addresses this economic lag. These questionnaires all consist of written questions that are answered on likert scales. As an example, question 1 on the AQ is "I prefer to do things with others rather than on my own," to which one responds "definitely disagree," "slightly disagree," "slightly agree," or "definitely agree" (Baron-Cohen et al. 2001: 15). In case of the ADOS there are 50 questions that are answered on the above 4-point scale, in the case of BAPQ there are 36 questions entered on 6-point scale, and in the case of the SRS there are 65 questions rated on a 4-point scale. The SRS, comfortably the longest of these questionnaires, still only takes 15-20 minutes to complete (Constantino et al. 2003: 428). Such measures, thus, greatly reduced the amount of time required to procure diagnostic information needed for genomic analyses. And yet, the drive to shortening the diagnostic process continues: various short-form versions of both the AQ and SRS have been created that consist of 28, 20, and 10 questions in the case of the AQ and 30 and 11 questions in the case of the SRS (for details see Nishiyama et al. 2014: 996).

These instruments also reduce the reliance upon highly trained clinicians or researchers who would previously be needed to administer interviews or observations and who are, of course, expensive to train and employ. The AQ and the BAPQ are both self-administered and, while the SRS was originally devised to be completed by teachers or parents (Constantino et al. 2004: 720), a self-administered version of the SRS has more recently been produced (Constantino & Cruber 2012). Completion of questionnaires,

[7] While questionnaires are sometimes used as screening tools the ADI and the ADOS remain core instruments for clinical diagnoses. These quotations do, however, also demonstrate that whether these questionnaires are primarily oriented towards an investigation of the cause or the diagnosis of autism is not a straightforward matter. Those involved with the development of the AQ, for example, "…wish to underline that the AQ is not a diagnostic," whilst also asserting its utility in "distinguishing individuals who have clinically significant levels of autistic traits" (Baron-Cohen et al. 2001: 14, 15). Researchers developing the SRS describe it as "…an effective surrogate for the diagnosis of autism in linkage studies" (Duvall et al. 2007: 657). What these passages remind us, and this is as true for social scientific analyses as the scientific work itself, is that epistemology and ontology in psychiatric diagnoses are mutually constitutive and it is hard to examine one without the other (Pickersgill 2011). See Bonnie Evans' work *The Metamorphosis of Autism* (Evans 2017) for further discussion in relation to autism.

therefore, requires no expert guidance and measures can be, and often are, completed away from the clinic or online (e.g. Hoekstra et al. 2011). Furthermore, questionnaire scores simply need to be tallied and, thus, results are unambiguous, require minimal interpretation, and further reduce the need for trained experts. In sum, addressing an economic lag by making the procurement of diagnostic information affordable with an LTS dependent upon behavioral data from huge numbers of people was a central rationale behind the emergence of these short-form questionnaires.

If the economic issue of affordability is important to genomic analyses, the issues of sensitivity and quantification are of crucial technical importance. As noted above, for reasons of statistical power it is increasingly seen as important that endophenotypes—sub-clinical behaviors regularly exhibited by genetic relatives of those diagnosed with autism—come under examination (Duvall et al. 2007: 658; Losh et al. 2009: 519). As discussed above, however, existing diagnostics are generally perceived as insufficiently sensitive to capture endophenotypes with ceiling effects ensuring that important endophenotypic data are lost. Those developing novel questionnaires stress that avoiding such ceiling effects must be a priority (Baron-Cohen & Wheelwright 2004: 167; Wheelwright et al. 2010: 2). Similar traits to those examined on the ADOS, therefore, are examined in the questionnaires though questions that are designed to be more sensitive to subtle impairments, such as "[p]eople ask me to repeat things I've said because they don't understand, 1 [very rarely] - 6 [very often]" (BAPQ; Hurley et al. 2007: 1688) and "I frequently find that I don't know how to keep a conversation going, definitely agree - definitely disagree" (AQ; Baron-Cohen et al. 2001: 15).

Closely allied to this issue of sensitivity is that of quantification; it is important for genomic analyses that questionnaires are able to identify not only those exhibiting endophenotypes but also locate both clinical and non-clinical individuals within a normally distributed population (Wheelwright et al. 2010: 2) and, potentially, within a particular subgroup, so that genes associated with a particular symptom cluster may be identified. That these questionnaires are able to perform such tasks is described as their "major advantage" over existing diagnostics:

> The major advantage of the Social Responsiveness Scale [over the ADI] is that it measures these highly heritable characteristics on a quantitative scale, rather than relying on the qualitative diagnosis of autism. (Duvall et al. 2007: 657)

The "quantitative scale" for the SRS is an individual score between 0 and 175—a normally distributed "autism spectrum" (Sucksmith et al. 2011: 361) that extends throughout the general population. The AQ is scored similarly, with individuals placed on a continuous distribution of between 0-50 or 50-200 depending upon the variant being used (Hoekstra et al. 2008: 1565). The BAPQ, meanwhile, takes a different approach to quantification with mean scores (between 1 – 6) presented. Additionally, authors in all cases emphasize that questionnaires can be used to tease apart various endophenotypes relating to particular behaviors, thus demonstrating their capacity to correct the "critical problem" (MacKenzie and Wajcman 1999: 17) of existing diagnostics.

To reiterate: despite the wide range of uses found for these questionnaires (see below) they were explicitly pitched as discriminative instruments (Nishiyama et al. 2014: 994) for use in genomics. John Constantino, co-creator of the SRS, is a practicing geneticist who immediately employed his own scales (e.g. Duvall et al. 2007). Hurley et al., in their paper first detailing the BAPQ, conclude by stating that:

> The BAPQ is likely to find numerous uses in the increasing number of studies aimed at characterizing the milder expression of the genetic liability for autism in non-autistic relatives of autistic individuals. (Hurley et al. 2007: 1688)

In relation to the AQ, Bishop states that:

> Compared with other methods of identifying the broad phenotype, the AQ has the advantage of being extremely quick and easy to administer, which means it has considerable potential for use in genetic studies that would benefit from a means of rapid phenotyping of large samples of individuals. (Bishop et al 2004: 1432)

And it is not just in the authors' own work that these questionnaires are used to undergird genomic analyses. These scales are standard measures for the largest genomic collections in the world, such as the Autism

Simplex Collection (Buxbaum et al. 2014) and the Simons Simplex Collection (Fischbach & Lord 2010[8]; see Singh (2014) for more on this collection programme). These questionnaires are, in short, key components of the LTS facilitating a genomic autism.

**Discussion and Conclusion: Mobile technologies**

In the previous sections I have detailed the importance of questionnaires to ongoing research in autism genomics, suggesting that numerous questionnaires were developed in the first years of the twenty-first century in order to address a crucial "reverse salient" in genomics that arose because of issues with the affordability, sensitivity, and quantifiability of existing diagnostics. Without these newly developed questionnaires, I have argued, it would have been much harder for genomic science to progress.

This account is, in part, intended to complement or correct those narratives that focus exclusively upon genetic sequencing and extraordinary computing power when discussing biotechnology generally and emerging technologies in psychiatry specifically. I have argued that these undeniably important advances need to be understood as part of a much broader technological system (Hughes 1987). A failure to consider extensive systems risks a "reheated futurism" (Edgerton 2008) of which STS accounts of biomedicine have previously been accused (Kerr 2004; Michael 2003; Raman & Tutton 2010), a disservice to the scale and mechanisms of innovation, and under appreciating the entanglements of the exotic and the mundane (Michael 2003).

This corrective is not the only, or even main, reason why social scientists should continue to foreground questionnaires, however. MacKenzie and Pardo-Garcia state that innovations involve the:

> ...re-use of existing resources (ideas and other cultural resources as well as artefacts), not the mechanical implementation of a grand plan nor simply logical deduction from existing scientific theory...the making of devices involves putting together, retuning and refashioning systems. (MacKenzie & Pablo Pardo-Guerra 2014: 157)

[8] Full collection details for the Simons Collection available from: https://sfari.org/resources/autism-cohorts/simons-simplex-collection/ssc-instruments

MacKenzie and Pardo-Garcia's analysis here hints at the existence of what Edgerton has called "'creole' technologies, technologies transplanted from their place of origin finding uses on a greater scale elsewhere" (Edgerton 2008: xiv). The AQ, perhaps the most culturally significant of the questionnaires considered here, has proven to be a highly mobile, creole technology *par excellence*, and it has done far more than simply facilitate genomic research. To give a flavor of this influence: First, the AQ has been translated into numerous languages—including Chinese, Dutch, French, Italian, Japanese, Persian, and Polish (Ruzich et al., 2015: 10)—allowing the AQ to become embedded in practice around the globe. Second, the self-administered nature of AQ ensures that people can pick up these questionnaires themselves and use them as they see fit, operating outside of scientific institutions (see Murphy (2006: 143) for more on the diverse uses of questionnaires). Thus, the AQ has contributed to the wave of popular cultural attention that autism has attracted, due to being included in the pages of *Wired Magazine* (Silberman 2001) where readers were invited to "take the test." Meanwhile the UK television program *Embarrassing Bodies* hosts an online "Mind Checker" that includes an online version of the AQ, which has been taken over 1.5 million times as of August 2017 (Channel 4 2014). Third, the AQ has been adopted in scientific communities operating at quite some distance to genomics. Jobe and Williams White (2007), for example, attempt to understand the nature of students' relationships, and the loneliness that some of those students experience, through the language of autism. As the work of Hughes and Callon might suggest, these researchers did no pick up the AQ as if from a "well-stocked supermarket" (Callon 1981: 24) but, instead, torqued it for novel ends. In this context the AQ is not deployed to reveal something about autism genomics, but to examine personality traits that influence "..the enjoyment of close friendships, loneliness, friendship quality, and negative interactions within a friendship" (Wainer et al. 2013: 2420). What these examples illustrate is that, while the AQ must be understood as being entangled with genomics, it has no inherent "categorical integrity" (Hughes 1986: 289) and cannot be reduced to it. Nor can we understand the AQ simply as a tool undergirding genomic research, for this is to miss a myriad of uses that warp and transform the AQ in different settings.

A crucial task awaiting those researching the sciences of autism—and for those who wish to understand LTS within contemporary biomedicine—is to trace these technologies in full, beyond the laboratory and into the field where scientists cede both exclusive access and a significant degree of control (Lorimer 2015: 102). This is not just an epistemically important task, but also an ethical one. Edgerton has argued that a

consequence of focusing upon mundane technologies like, I would argue, questionnaires is that "…we shift attention from the new to the old, the big to the small, the spectacular to the mundane, the masculine to the feminine, the rich to the poor" (Edgerton 2008: xiv). Whereas accounts of geneticization, genomicization, and molecularization have been accused of universalizing "a form of biopolitics within globalization that is specific to the zone of 'liberal peace' in the affluent spaces of the west" (Braun 2007: 25), an examination of questionnaires and their ilk reminds us that that biotechnical knowledge extends far beyond the walls of the life sciences department (Raman & Tutton 2010: 721) or genetic clinic. Any attempt to understand the impact of emerging technologies on biomedicine, psychiatry, or autism, and which seeks to be "genuinely global" (Edgerton 2008: xiii), must conceptualize technology more broadly.

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