

Contours and Constraints of an Autism Genetic Database

Scientific, Social and Digital Species of Biovalue

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Abstract: This paper examines the *scientific, social* and *digital* processes that shape multiple forms of biovalue evident in the development, participation and use of the Simons Simplex Collection (SSC), the largest autism genetic databases in North America. Based on interviews with SSC study participants and investigators, as well as a content analysis of a range of SSC materials, this empirical study makes visible the various contours of biovalue that are entangled between scientists who use this data for autism research, families who donate their blood and medical information to gain access to needed resources, and digital networks of exchange that make hybrid connections between and among these emergent biosocial communities. By examining the production of and interactions between scientific, social and digital forms of biovalue this paper highlights the constraints embedded within this heterogeneous assemblage to offer a critical account of the limits of the SSC and subsequent knowledge production. I contend that while the multi-dimensionality of biovalue built into the fabric of the SSC structure creates various contours of biovalue, it structurally constrains the types of production and knowledge flows that are allowed to be conceived and generated.

Keywords: autism; genetic database; biovalue; biosociality; digital networks.

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The power of the Simons Simplex Collection (SSC) to clarify the genetic basis of autism spectrum disorder has been made abundantly clear over the last two years...landmark findings are a testament to the creativity of the researchers, as well as to the inspiring commitment of the more than 2,600 families who took part in the SSC.

(Senior scientist at Simons Foundation Autism Research Institute)

My family entered the study and it felt like we were part of a community working towards healing. Then we were given the opportunity to join the Interactive Autism Network. We thought it would be wonderful to join so that we could be part of a larger community dedicated to connecting parents as well.

(Parent who participated in the Simons Simplex Collection)

1. Introduction

The development, participation and use of disease specific genetic databases in the 21st century is producing selective forms of value embedded in collected samples and creating distinctive relationships and exchanges among and between scientists and research participants. As indicated in the opening epigraphs, data collected for the Simons Simplex Collection (SSC), an autism genetic database, holds exceptional value for scientists of current and future research on autism genetics. At the same time, on-going participation through digital networks creates a distinct community among those who donate blood and medical information for specific genetic research endeavours like the SSC. The emergence of these processes and relationships is due in part to the changing dynamics of the collection, participation and use of genetic information for scientific research on complex human conditions. For scientists, we are seeing a shift from individual investigators collecting data to conduct their own research to collaborative research consortiums working together to develop genetic databases and large multi-sited scientific research networks. For research participants, the donation of blood and medical information may not be a one-time affair, but rather consist of on-going participation and an opportunity to be part of a larger community. Within this context, distinct configurations of participation and research are emerging in genomic science that are shaping various forms of biovalue. The purpose of this paper is to empirically investigate the contours and constraints of biovalue situated within these emergent scientific and biosocial processes.

2. Species of Biovalue and Emergent Biosocialities

Science, Technology and Society (STS) scholars have engaged with both the economic and biosocial exchanges and assemblages involved in the development, participation and use of national biobanks (Tutton and Corrigan 2004; Peterson 2005; Busby 2006; Tutton 2007; Hoeyer 2008) and disease specific genetic databases (Novas 2006; Haddow et al. 2007; Callon and Rabeharisoa 2008; Dixon-Woods, et al. 2008). Ideas about the relationship between the life sciences and capitalization have been articulated within STS through concepts such as “bioeconomics” (Rose 2001) and “biocapital” (Sunder Rajan 2006), and “life as surplus” (Cooper

2008). Catherine Waldby (2002) developed the concept of biovalue, or what she describes as in-vitro vitality produced by the biotechnical reformulation of living processes. More specifically, tissue economies of blood, organs, and cell lines in neoliberal capitalism alongside emergent biotechnologies have enabled donated tissues to take on multiple uses and adopt multiple trajectories (Waldby and Mitchell 2006). In this process, tissue donations are transformed from an act of direct civic responsibility between fellow citizens (e.g., voluntary blood donation) into a complex network of donor-recipient relations heavily mediated by biotechnical processes and a range of institutional complexes. In such instances, we learn how tissues are open to the micro-technical manipulation of productivity and in genomics research, an opportunity for “new circuits of bioproductivity” that can be “mined” indefinitely to contribute simultaneously to public and private value in the present and in the future (Mitchell and Waldby, 2010, 340).

To better understand STS contributions examining the relationship between the life sciences and capitalism Stefan Helmreich (2012) conducted a genealogical analysis of scholarship on biocapital. He identified two theoretical strands, including 1) Marxist feminist approaches, which occupy questions of the binary between productive labour (labour that has monetary value) and reproductive labour (labour that is not associated with a wage) and 2) Marxist Weberian approaches that focus on questions of meaning, information management, and speculation. In the latter, “value in the market sense and value in the ethical sense co-constitute one another in biocapital” (Helmreich 2012, 465). Both of these clusters engage with Marx’s political economy and Foucault’s biopolitics, since they both consider the integrative analysis of economy, society, and politics (e.g., Marx), as well as mechanisms through which life processes are controlled under systems of authority over knowledge, power, and the processes of subjectivism (e.g., Foucault). In the advent of emergent biotechnological innovations, like genomic science, Helmreich identifies new kinds of financial speculation, academic-industrial biotech hybrids, and the new relations of commoditization embedded in notions of biocapital. Importantly, for the purposes of this paper, Helmreich’s genealogical representation of biocapital offers ‘different species’ of making biology into capital, which he describes as an unstable process consisting of exchanges that correspond to “economic, cultural, social, and symbolic species of capital” (Helmreich, 2012, 474). I interpret Helmreich’s genealogy to suggest that classifications of biocapital can take different formulations of (as well as move beyond) financial exchanges thereby opening up the multi-dimensionality of various forms of negotiated systems of value exchange.

More recently, concrete examples of the hybridity and multiplicity of biovalue has emerged based on research of data-intensive infrastructures, including biobanks (Hauskeller and Beltrame 2016; Tempini 2017; Timmons and Vezyridis 2017;) Christine Hauskeller and Lorenzo Beltrame

investigated public and private umbilical cord blood (UCB) biobanking practices and the circuits of UCB biovalue. They found that rather than a dichotomous private-public distinction of economies (e.g., solidarity versus profit), there is an overlap and hybridization between distributive and market economy of UCB. Through different scenarios of UCB donation, they identified analytical distinctions between social, cultural, and biopolitical implications within different regimes of UCB banking—distinctions ranging from life-saving tissue to promissory objects for future use. They contend that these complex bioeconomies coexist and hybridize into exchange systems that do not operate within dichotomous distinctions between public and private (Hauskeller and Beltrame, 2016). Niccolò Tempini (2017) also engages with the multi-dimensionality and hybridity of value by investigating the creation of value in an online community and data-intensive infrastructure called *PatientsLikeMe* (PLM), a social media network for patients. In this example, Tempini identifies four dimensions of value in PLM that depend on the situation of digital data use and circulation, including business, scientific, community, and individual values. For example, scientific value is generated when the data on PLM provides good evidence for conducting health research (e.g., peer review publications). Community value, on the other hand, is generated when the data on PLM can be used to foster social interaction and inclusive communities (Tempini, 2017, 196). Like Hauskeller and Lorenzo, Tempini also recognizes these different values as both multidimensional and situated, where “different kinds of value creation require different sets of engagements with data” (2017, 207). Collectively, these examples offer insightful distinctions about the production, multi-dimensionality, and hybrid contours of biovalue that are developing at the intersection of large data collections involving a heterogeneous assemblage of many actors and materials.

The ideas of ‘different species’, multi-dimensionality and situated shaping of values in relation to and beyond the early notions of biocapital and biovalue offer insight to the current analysis of actors and biomaterials circulating within the Simons Simplex Collection (SSC). This framing opens the opportunity to investigate the heterogeneity and interconnected biovalues embedded in scientific, social and digital networks of exchange. It is through the development, production and use of these different species of value that we begin to see how biovalue, can be more than the production of commodities that creates financial value; it also entails “the embodiment of intellectual, relational, and emotional resources and capacities” (Birch and Tyfield 2013, 314). As I make evident in the pages that follow, not only do the social and ethical values enable the production and exploitation of scientific and/or economic biovalue in the SSC, these different situated values are also interconnected and co-constitutive of each other. By unpacking the dynamics of these multi-dimensional contours of biovalue, this study offers a nuanced empirical example of the reciprocal and hybrid expressions of biovalue generated

within a heterogeneous assemblage of people, data, and digital networks of exchange. This case study also makes visible the knowledge and biosocial constraints built into the SSC due to the strict criteria for inclusion and the preconceived genetic hypothesis driving the development of this autism genetic database.

Alongside these new circuits of bioproductivity is the emergence of new social relations and collectivities; or what Paul Rabinow (1992) refers to as biosociality. These new forms of social relations are emerging based on people's shared biological identities related to particular bodily conditions such as genetic diseases or illness identities (Rabinow 1992). Social connectedness through corporeal or genetic linkages is especially evident in groups that come together to share experiences or advocate for particular diseases. Paul Rabinow and Nicolas Rose describe this phenomenon as "strategies for intervention upon collective existence in the name of life and health," which are now being specified in terms of emergent biosocial collectivities based on specific genetic diseases (Rabinow and Rose 2006, 197). Chloe Silverman draws on the collectivizing elements of biosociality in autism genetics research based on parent activism in autism science. She argues that parent advocates who speak for people with autism are "legitimated by multiple affinities built on genetic associations and physiological parenthood" (Silverman 2008, 39-40). Silverman argues that genetics establishes a language of affinity and kinship, which serves as a basis for forming biosocial communities.

In the context of donating biomaterials to disease specific biobanks or genetics research that collects large numbers of samples based on a particular disease, there are various ways people come to participate and the types of social connectedness that prevails (Dixon-Woods, et al. 2008; Michie et al. 2011; Singh 2015). For example, families who donated to a cancer tissue bank viewed their participation as a way to become embedded within disease-specific communities; forming "cooperative hybrids" with scientists that rely on "trust, solidarity, shared values" (Dixon-Woods 2008, 76). I also investigate biosociality at the community level based on participation in an autism genetic database, where families of a child with autism felt obligated to participate to help their family and become more involved in the autism scientific community (Singh 2015). The families also conveyed a sense of altruism to participate in order to help the broader autism community. Both of these narratives of participation were tied to the shared emotional experiences of raising a child with autism. As these studies convey, biosociality takes on many different contours that can be shaped by genetics research itself through the language of affinity and kinship, the desire to be part of disease communities, and the shared corporeal vulnerability and somatic suffering.

In the case of SSC, biosociality takes on new contours that manifest through the act of donating blood and medical information to an autism genetic database in combination with continued participation and virtual connectivity with other SSC families. These families are brought together

based on their shared experiences of having only one child diagnosed with autism and biosociality is sustained through digital networks that keep SSC families engaged in a unique autism genetic community. However, I argue that these forms of biosociality are constituted based on the assumptions built into the SSC, which was designed to bring specific groups of people together in order to test a unique genomic hypothesis. Even though virtual modes of interaction were developed to bring together SSC families, these collectives are strictly defined based on the priorities deemed most useful for scientists who conduct genetics research on autism. Thus, the ideas of autism genetic causation and the biomedical classification of autism shape the kinds of biosocial configurations that coalesce around the SSC. I contend that while these biosocial communities are beneficial to the families who participate, they are limited to those families who meet the strict inclusion criteria for SSC, as well as those who choose to remain in contact with the SSC through digital networks of exchange.

Within the contours of biovalue and biosociality discussed above, the aim of this paper is to empirically investigate the multi-dimensionality of biovalue entangled within the production, participation and use of the SSC and how these different forms of biovalue are interwoven and mutually constitutive of each other. As I make evident throughout the paper, these different contours of biovalue and biosocial communities that take shape within the SSC are based on a particular kind of family and specific characteristics of autism, which I assert creates new forms of collective identity and technoscientific exchanges and futures for scientists and research participants alike. At the same time, I argue that these emergent research assemblages build constraints on the kinds of knowledge generated and possibilities for further research on autism.

This paper offers several distinctive contributions that set it apart from other STS analyses of genetic databases in the context of biovalue and biosociality. First, the SSC is an autism specific database, not a population database. Compared to national gene banks that collect biomaterials and clinical information from the general population, the kinds of biovalue generated by families who participate in the SSC holds a different set of meanings given their embodied experiences with autism. Second, the SSC is derived from a very selective group of families who have one child diagnosed with autism (e.g., simplex families), which was specifically designed to identify spontaneously acquired genetic mutations that scientists believe are the cause of some forms of autism. The clinical characterization of the child with autism and their family also had to meet certain criteria for inclusion; strict criteria that holds particular value for scientists. Thus, the specific genetic mechanism, family structure and strict inclusion criteria creates an opportunity to critically analyse the kinds of knowledge production, biosociality, and data flows that are produced and constrained within these scientific boundaries. Third, this study investigates multiple actors involved in the funding (Simons Foun-

dation), development (study coordinators), participation (families) and use (scientists) of the SSC, as well as digital platforms that are uniquely designed to sustain the relationship among these hybrid collectives. This heterogeneous assemblage allows me to investigate the relationship between the SSC and multiple actors, the controversial processes in the development and use of this collection (Canada et al. 2014) and the different forms of clinical labour (Mitchell and Waldby 2010) needed to maintain persistent links between scientists, participants, biospecimens and data in all their multiple forms.

3. Methodology

To investigate the social, scientific, and digital forms of biovalue embedded in the development, participation, and on-going use of the SSC, this paper draws on various sources of primary data, including: in-depth interviews with parents who participated in the SSC (N=23 SSC families) and researchers who were involved in the SSC data collection (N=9). I conducted the interviews between 2008 – 2013, which were recorded, transcribed and coded for central themes using grounded theory methods, including open and focused coding, theoretical memo writing, and generation of themes (Charmaz 2006). This study received IRB approval to conduct interviews from Georgia Institute of Technology, protocol H12077.

A second set of data consists of a content analysis of 78 scientific articles that have used the SSC database as a primary resource. These articles were analyzed to determine the type of scientific knowledge being produced using the SSC. Scientific articles were identified by conducting a literature search in three databases in September 2017 using the search term “Simons Simplex,” including PubMed (all fields), Web of Science Core Collection (title/keyword/abstract), and PsycINFO (all text). I also added scientific articles featured on the Simons Simplex Community@IAN (Interactive Autism Network) and the Simons Foundation Autism Research Institute (SFARI) websites, to account for any articles not identified through the database searches. I collected the scientific articles in Endnote referencing software and coded for type of autism research conducted (e.g., genetic causation, environmental causation and/or, symptom measurement – phenotype).

A third set of data is a selective content analysis of two websites. The first is the SSC Community@IAN website, which displays public information and serves as a digital network of 1,500 SSC families who want to remain in contact with SSC investigators and other SSC families. I determined the type of SSC-based research reported to families through this digital exchange compared to the scientific literature identified above. The second is the Simons Foundation Autism Research Initiative (SFARI) website, which is the web portal of information about SSC that offers in-

formation to researchers on how to order SSC samples and/or recruit SSC families using the SSC Community@IAN. These two websites were analyzed to establish the types of on-going transactions between and among parents and scientists who are involved with the SSC.

Collectively, this data makes visible the types of scientific, social, and virtual relations, forms of knowledge exchanges, and biovalue that are emerging in the flows of scientific development and use of the largest genetic database designed to investigate specific genetic mechanisms associated with autism.

4. A “Cadillac Resource” for Autism Genetic Research

The Simons Simplex Collection (SSC) was funded by the Simons Foundation, a private non-profit philanthropy founded in 1994 by billionaire Jim Simons and his wife Marilyn. Jim Simons is a MIT trained mathematician and founder of one of the world’s most successful Wall Street Hedge funds. Marilyn Simons is an economist and currently president of the Simons Foundation and board member at the Cold Spring Harbor Laboratory, a research facility specializing in molecular biology and genetics. Initially, the Simons Foundation focused their philanthropy by donating tens of millions of dollars to math and science endeavors worldwide. In 2003, the Simons Foundation formalized their investments in autism research by starting the Simons Foundation Autism Research Initiative (SFARI). SFARI’s goal was to increase the scientific understanding of autism spectrum disorders in order to benefit individuals and families challenged by these disorders. The foundation would focus on developing tools that scientists could use to enhance their understanding of autism.

One of the first major projects launched by SFARI was the Simons Simplex Collection (SSC). In 2006, the goals of the SSC were set by SFARI to recruit and carefully evaluate DNA and clinical information of more than 2000 autism families from twelve university research clinics throughout the United States and Canada (SFARI nd-a). At the request and advisement of scientists working in the field of autism genetics, the SSC would be different from other autism genetic collections¹.

First, the SSC was starting from the ground up, what Mitchell (2012) refers to as a *de novo* approach, where the standardization of biospecimen and clinical information is collected and stored in one uniform manner. As I will discuss in more detail below, the SSC was designed to identify certain types of genetic mutations, which required a certain kind of family structure as well as detailed clinical measurements of autism. The SSC was also designed to recruit and collect data in academic based clinics already serving children with autism and their families. It was presumed that this would not only allow scientists to easily recruit families to

participate in the SSC but also enable allow scientists to effortlessly re-contact families for follow-up studies. The design and scope of the project would not only make the SSC one of the largest autism genetic databases available to scientists and provide a unique genetic collection with associated data consisting of detailed and precise characterization of the individual with autism and their family. As they saw it, “rigorous phenotyping maximizes the value of the resource for a wide variety of future research projects on the causes and mechanisms of autism” (SFARI nd-a). Consequently, scientists refer to the SSC as the “Cadillac resource” for conducting autism genetics research; a metaphor or scientific practice of branding (Tupasela 2016) that identifies how a large database of clinically and genetically precise data is superior to previous autism genetic collections. This type of branding has significant symbolic and strategic value, since the scientific and potential financial gains through diagnostic and treatment developments will be accrued further downstream (Tupasela 2016).

From the beginning of the project, the SSC took a venture capitalist approach to establish a resource that would be of significant value to science. I characterize the SSC in this way because when data collection started in 2008, genetics research on autism had limited successes in finding major genes associated with autism. The SSC was developed based on scientific data that suggested rare spontaneous genetic mutations were involved in a small number of autism cases. The SSC was specifically designed to test this hypothesis with no guarantee that this genetic mechanism would reveal clues to the causes of autism. At the time, it was one of the only leads autism genetic scientists had after millions of dollars of private and public investments had been made in autism genetics research (Singh 2016). Strategically, the Simons Foundation made investments in scientists who were not necessarily studying autism, but who were leaders in a particular scientific field. As one autism genetic scientist involved in the collection stated:

Some of the best researchers, not in autism, but some of the best neural scientists and functional biologists and geneticists and such...came to the table simply by virtue of money. (SSC scientist interview #1)

Thus, in autism science, as with certain types of financial data, the Simons Foundation made calculated investments based on past performance, which according to Jim Simons is the “best predictor of success” (Regalado 2005). No private philanthropy has made the kinds of financial investments toward autism research as the Simons Foundation, which currently has a budget of \$75 million dollars a year and since 2007 has “provided or committed \$380 million in external research support to more than 400 investigators in the U.S. and abroad” (SFARI nd-b). A major part of this investments was the development of the SSC. The collection of data for the SSC was completed in 2011 by twelve collection sites

in the U.S. and Canada that acquired samples from 2,644 simplex families, making it one of the largest autism specific databases in the world.

5. Contours and Constraints of Biovalue

There are many species of biovalue shaped through the processes of developing the SSC and the type of data available for subsequent use. I identified three multi-dimensional contours of biovalue situated within the interconnections between scientific, social and digital networks of exchange consisting of various forms of biomaterials, data, and knowledge production. While these contours are not mutually exclusive, this framework helps to highlight the various domains of biovalue embedded in the development and use of the SSC for the scientists who use the data, the families who participate in the database, and the hybrid collectives they form through digital networks of exchange. Further, these different contours help to distinguish the constraints and consequences of knowledge production and flows that are bounded within the selective criteria used to develop the database.

5.1 Scientific Biovalue: Family Structure, Clinical Precision and Biomaterials

Scientific biovalue was structured into the SSC from the beginning in order to test the hypothesis that rare *de novo* (spontaneous) copy number variants (CNVs) are present at a higher rate in children with autism than in unaffected children (CNVs are small genetic deletions or duplications in the genome) (Singh, 2016). Given this genomic style of thought, the SSC is comprised of DNA and clinical information from families with only one child diagnosed with an autism spectrum disorder (ASD), both biological parents, and one unaffected sibling (i.e., simplex families)². Based on this research design, scientists are working under the assumption that rare *de novo* CNVs account for a significant fraction of autism with unknown causes and in order to find these genetic mutations, thousands of simplex families are needed. Thus, the simplex family structure holds particular value for autism genetic scientists who are in pursuit of identifying and understanding the relationship between autism and CNVs. As I discuss elsewhere (Singh 2016), this emergent technoscientific approach offered scientists a path forward in what was essentially a failed attempt by the scientific community to find any major genes for autism despite large investments of time, people, and money.

The SSC also placed significant attention to collecting precise clinical data of the families who participated. Before the SSC was developed, a major challenge for scientists using other collections of autism genetic samples was the lack of consistent and reliable collection of clinical data³.

Further, the heterogeneity of autism symptoms and lack of clear and distinct clinical phenotypes (traits) makes research on autism genetics challenging. Thus, the SSC sought to collect detailed, valid, and reliable clinical data so that scientists could make meaningful genetic correlations to autism phenotypes. To achieve this level of integrity in the clinical data, the SSC evaluated the autistic child with a battery of diagnostic measures and standardized instruments. SSC clinicians were also trained by a set of expert clinical psychologists and each diagnostic evaluation was validated every quarter. This rigorous approach to measure autism symptoms was taken to ensure that each SSC site was uniformly collecting the clinical data. As indicated below, this level of detail also served in the interest of parents who were seeking an autism evaluation and services for their child. In the end, approximately 6,000 phenotype variables were collected from each family (SFARI nd-a).

The challenges of accomplishing the ambitious goals of the SSC were evident from researchers and coordinators involved in the initial stages of recruiting families and collecting data. Although the rigor and uniformity of the data in the SSC sets it apart from other autism genetic databases, establishing this type data was challenging for SSC collection sites. In 2008, when I was first inquiring about the project, one SSC coordinator expressed to me how many of the investigators were dismayed and frustrated by the ‘corporate’ or ‘business-like’ structure of the project. Researchers working at these collection sites did not feel comfortable with the strict inclusion criteria and felt some families were getting overlooked that may be of importance to the collection. Any resistance to the strict inclusion criteria had consequences. I learned that one clinical research site was dropped and no longer funded by the Simons Foundation because of conflicts over diagnostic procedures and whether a child met the inclusion criteria. One coordinator compared the SSC recruitment process to a pharmaceutical clinical trial rather than a clinical research study on autism, since clinical trials typically require strict guidelines for inclusion in order to show very small clinical significance of drug effectiveness. In this sense, the construction of the SSC was developed with strict inclusion criteria to identify specific and rare genetic pathways of autism, which could subsequently be therapeutic targets or at the very least reveal “clues that could lead to important breakthroughs” (SSC recruitment flyer, 2010).

It was also evident from interviewing researchers involved in collecting data for SSC that creating the collection was a major investment in time and money. On average, it took at least two months to recruit and evaluate the families, which made the strict exclusion criteria a point of concern, especially when each group was held accountable to meet their quota of 20-25 families each quarter. These efforts reflect a different type of clinical labour (Mitchell and Waldby 2010) that extends beyond participation in genetics research to include the time intensive and stressful processes experienced by study personal who were required to work un-

der strict guidelines and timeframes to meet research obligations.

In addition to the simplex family structure and detailed clinical characterization of the sample, the range of biological materials available to researchers offers extensive possibilities for scientific investigation and hence, biovalue. According to the SFARI website there is a variety of SSC biological materials for sale that scientists can purchase and use for their research, including DNA, plasma (a liquid form of blood), and lymphoblastoid cell lines (cell lines that live indefinitely). The technoscientific transformation of all SSC blood samples into lymphoblastoid cell lines is deemed extremely valuable for science because these immortalized cell lines offer a renewable supply of DNA for future genetic studies. The most recent biospeciman created are induced Pluripotent Stem Cells (iPSCs), which are cells derived from SSC blood samples that have “essential properties” of embryonic stem cells. According to the SFARI website, these iPSC cell lines can develop into brain cells and have become, “a valuable model in autism research, complementing research studies in animal models” (SFARI nd-c). The developments of these different biomaterials are examples of how the SSC is being maximized through biotechnical processes, where new forms of biovalue are being generated through the various transformations of blood donated from SSC families.

The SSC also provides genetic information generated from whole genome sequencing (WGS). This data is yet another micro-technical manipulation of productivity. Scientists have described the availability of WGS as the next frontier of scientific trajectories of the SSC and genomic science more broadly. In August 2017, SFARI announced that a total of 8,975 whole genomes from the SSC have been sequenced, most of which are currently available for use by all approved researchers (SFARI 2017). In addition to WGS, numerous other SSC genomic and transcriptomic data sets (e.g., RNA transcripts that are produced by the genome) are available for use by scientists. These genomic products are highly valued by scientists given the computational power that can analyze and interpret the data, as well as the seamlessly endless types of experiments that can be conducted using genomic information. As the SSC biomaterials remain available and continue to mutate, the future technoscientific transformations will undoubtedly create new and extended forms of scientific biovalue. This reflects Mitchell and Walby’s (2010, 340) articulation of how biovalue is embedded in the biological samples themselves, where they “can be retained and repeatedly mined for a variety of research,” and “potentially open to new techniques, methods, and research questions that develop in the future”. Indeed, the SSC has this potential through these various technoscientific products, which is harnessed by the ability for scientists to remain in contact with families to collect additional biospecimens as needed; a contour of biovalue which I discuss in more detail below.

5.2 Social Biovalue: Diagnostic Currency and Genetic Answers to Autism

Accounting for and articulating the contours of biovalue constitutes not only the people who are involved in the collection and use of the SSC but also those who donate their blood and medical information. As Mitchell and Waldby (2010, 341, italics in the original) importantly point out, “*both* biobank managers *and* biobank participants are involved in formatting the data necessary for the bank’s creation of value. In this section, I investigate how parents place value in the SSC, which is related to their decision to enrol their families in an autism genetic database. Based on interviews with parents who participated in the SSC, a different set of biovalues emerged starting from the initial participation and need for answers to the anticipated outcomes of genetics research using the SSC, especially for the causes and treatments of autism.

The clinical labour involved in donating blood and medical information to the SSC consisted of two visits to one of the affiliated university clinics, where participants completed an extensive parent interview and evaluation of the child with ASD in addition to a blood donation from each family member. As I discuss elsewhere (Singh 2015) there were different narratives of participation from the perspective of parents who donated their family’s blood and medical information to the SSC (e.g., altruistic, obligated, and diagnostic parents). When viewed through the lens of biovalue, however, immediate and long-term benefits are evident in the data. First, the compensation for participation was a written research report that included information about the child’s diagnosis, cognition and adaptive behaviour, and recommendations for treatment. This diagnostic evaluation is a significant incentive since parents have to wait over a year to see a specialist who can accurately diagnose ASD. Further, the cost of a psychological evaluation is well over \$2,000, which many parents have to pay out of pocket since it is not typically covered by health insurance in the U.S. The parents were encouraged by the SSC research teams to use this evaluation to help qualify for services. Thus, for some parents, especially those who did not have an extensive clinical autism evaluation for their child, participation in the SSC offered what Singh refers to as diagnostic currency (2015). This currency took shape in many forms beyond a free diagnosis. First, a clinical diagnosis offered medical and social legitimacy for concerns parents experienced with their children. As one parent stated:

As a parent, when it’s your child, you just want the answers. (SSC parent interview #16)

Parents indicated that it was extremely stressful to be so worried about their child and not know whether something was truly wrong. An-

other parent whose son was never formally diagnosed before the study stated:

That's what we wanted first and foremost was somebody to say, okay, look, he's autistic. And then tell us what level he's capable of operating at...and you know, evaluate him and kind of help us figure out...the services that he needed. (SSC parent interview #14)

These parents wanted to know with certainty whether their child was on the autism spectrum and assumed that the detailed autism evaluation they received in exchange for participation in the SSC would allow them to seek the most appropriate care for their child. This is reminiscent of research on medically unexplained symptoms (Dumit 2006) and the uncertainty of non-diagnosis and questioning of others of the legitimacy of concerns, which can create significant doubt, distress and chaos. It is evident that these parents clearly wanted to close this gap of uncertainty through their participation.

The extensive evaluation also provided a gateway to autism services, which offered a second kind of diagnostic currency. For example, one mother who had twin boys diagnosed with autism was hoping that the thorough evaluation would help her obtain educational services. She stated:

I have been paying for evaluations for years and I've been struggling with my school district for years and any opportunity to have a good independent evaluation was something I jumped all over. (SSC parent interview #3)

This parent, like many others, viewed the SSC as an opportunity for her children to get a thorough autism assessment that would be helpful as she negotiated with the school district about qualifying and receiving special educational services. The detailed and free evaluation served as a bargaining document or form of currency in exchange for educational services. However, as I have highlight elsewhere, for some parents this document was not made available immediately and the interpretation of the results were hard to understand (Singh 2015).

Beyond diagnostic currency, parents also saw value in a large multi-sited study that was seeking answers to the questions of autism causation and treatment through genetics research. One of the first families to participate in the SSC who had a teenage son graduating from high school stated:

We were really excited to be a part of it just because I still don't know why Carl has to deal with this daily and I'd like to know; it would bring closure. (SSC parent interview #21)

Given the promotional nature of the SSC, many parents anticipated that the study would provide a genetic answer to autism causation, which in their minds would lead to targeted treatment. As one parent stated:

I am very interested in having scientists find out more about autism if there is some genetic link, make any advancements, and make it easier for the lives of these kids. (SSC parent interview #8)

Likewise, another parent was hoping that the database was going to help scientists:

Narrow it down and identify where some of the deficiencies are and it *may* be something that in the future they can impact. (SSC parent interview #3)

Parents did not speak of commercialization of the SSC or economic value gained from drugs and/or interventions developed from the data but were rather more optimistic and hopeful. It was almost as if by virtue of their donation the knowledge generated from the SSC would be made readily available to them in the future. Such economies of hope extend beyond a therapeutic cure or economic wealth to include how therapeutic benefits derived from biomedical research involving the donation of human biomaterials should be distributed (Novas 2006) Through these accounts we also begin to see how the realization of value stem from what Hoeyer (2016, 352) refers to as “nonknowledge,” where the “research questions themselves perform work similar to the one usually ascribed to certified answers and research results. Beyond the realization of financial and knowledge assets, these parents are relying on the expectations of the SSC to find the underlying genetic cause of autism and in a few parent accounts, possibly a cure. Thus, these participants are what Tutton (2007) refers to as “active recruits,” since they are deeply invested in the anticipated outcomes of the research and enthusiastically sought participation to help out in any way possible.

5.3 Biovalue Constraints and Consequences

Although different contours of biovalue are evident in the domains of scientific research and parent participation, I want to reflect for a moment to account for the constraints in these multiple formulations of biovalue. This section offers a critical analysis of constraints and consequences inherent in the structure of the SSC, which creates certain kinds knowledge flows and nonflows to borrow from Hoeyer et al. (2017). However, the nonflows in this case refer to the constraints in knowledge production that are embedded in what makes the SSC valuable, namely the simplex family structure, distinct definitions of autism, and strict recruiting mechanisms. Although appealing for scientists, the simplex fami-

ly structure is extremely limiting and embedded with inherent biases. First, it limits participation to only biological and heterosexual parents, which excludes many alternative family structures, e.g., parents who adopt, same-sex parents who adopt or have biological children, or single-parent families with no contact to the other biological parent of the child with autism. Although the strict inclusion and exclusion criteria is warranted given the goals of the SSC, the exclusion of these families limits not only the type of knowledge produced (e.g., *de novo* CNV knowledge), but also the potential benefits the study offers to families that participate (e.g., extensive autism evaluation). The prospective interventions will also presumably be made with this family structure in mind, and therefore likely be developed under the assumptions that families are heterosexual, middle class, and have access to healthcare, not to mention the time and resources needed to navigate autism services.

In addition to the limits of participation based on family structure, the families who participated in the SSC were predominately affiliated with one of the twelve research clinics that were recruiting families to participate. This creates additional structural exclusions since there is well-documented evidence to support disparities related to autism clinical service access based on race, ethnicity, and social class (e.g., Liptak et al. 2008; Magana et al. 2013). These disparities are additionally evident in the SSC, which underrepresents race and ethnicity of children with autism in this sample comprising of less African Americans (~4%) and Hispanics (~11%) compared to the 2016 U.S. Census (13.3% and 17.8%, respectively). White families, who represent 76.9% of the U.S. Census, on the other hand, comprise ~78% of the SSC (SFARI Base nd-a). Social class, measured by annual household income, also shows that the SSC is composed of mainly middle class (\$51,000 - \$100,000, 39.6%) and upper middle-class families (\$101,000 to >\$161,000, 38.9%) (Goin-Kochel et al. 2015). I do not mean to suggest that racial and class categories should be represented in the SSC to provide evidence for disparities based on biological differences, but rather aim to call attention to how this nonflow of knowledge obscures the understanding of upstream processes of unequal access to autism services (Epstein 2007). These demographics represent the inherent bias of the types of families who compose the SSC, which is likely a result of the structural constraints of accessing clinical autism services as a function of social class, which historically is associated with race, as African Americans are disproportionately working class and poor. In this case, people with limited financial resources are less likely to have access to autism clinical services, much less time to participate in research. This is important because it also limits access to the diagnostic currencies mentioned above, as well as the opportunity to be part of the virtual community of SSC families, which in addition to providing updates on research generated from the SSC samples, offers a range of additional information that would be beneficial to most families who have a

child with autism (e.g., employment, technology use, parenting strategies, etc.).

The SSC also consists of an over representation of male children with autism where males with ASD constitute 86.4% of the samples (Goin-Kochel et al. 2015). Although this bias reflects the ASD estimate of American boys who are 4.5 times more likely to have autism compared to girls, the SSC male to female ratio of children with autism is 6.5:1 (2292 males and 352 females). Not only does this imbalance place more emphasis on investigating male autism cases but also reinforces the notion that autism is a representation of the ‘extreme male brain’. This theory of autism promoted by Simon Baron-Cohen, an autism researcher at Cambridge University and current president of the International Society for Autism Research, attempts to explain the similarities between male traits and traits typically associated with autism (Baron-Cohen 2002). Again, these assumptions are built into the SSC and hold particular value for scientists. If the gender bias were in the reverse direction, e.g., female to male ratio of 6.5 to 1.0, the utility (and value) of the SSC would be questioned by scientists. Perhaps even more concerning in the context of this unequal representation based on sex is how the division in ASD based on sex is already translating into studies that are investigating gender differences in ASD characteristics (e.g., Frazier et al. 2014; Howe et al. 2015). These studies aim to identify differences in autism symptoms (e.g., behavioural symptoms, cognitive functioning, verbal ability) between males and females. Most troubling is the notion that these differences are rooted in genuine biological differences between males and females when it comes to behaviours such as “higher levels of irritability and externalizing behaviour in female patients,” which could imply according to scientists, “the need for greater monitoring of behaviour problems in female patients with ASD” (Frazier et al. 2014, 701). These limitations and gender biases in the sample, while valuable based on scientific assumptions of autism causality and sex differences, inevitably shapes the kinds of resources available for scientific research and the subsequent knowledge production and flows. In the case of sex differences in autism, the database and subsequent knowledge is built on social norms that promote the gender binary, as well as distinct characteristics deemed male over female (Epstein 2007).

5.4 Digital Biovalue: Interactive and Virtual Networks of Exchange

A third contour of biovalue manifests through digital networks that enable the purchase and flow of biological, clinical and genomic data between scientists conducting autism research and the Simons Foundation Autism Research Initiative (SFARI), the governing body of the SSC. Digital networks bring additional value to samples like the SSC since they establish shared databases, which can allow researchers to access the data

remotely. The organization and configuration of the SSC as a network biobank (Canada et al. 2015), where governance of biomaterials is centralized by SFARI, highly influences the needs for multiple ways of engaging with the SSC. Thus, SSC families who donated their blood and medical information are also brought into this digital network of exchange. These digital and virtual interactions bring scientific sustainability to projects like the SSC but also generate new forms of biosociality among the families who were brought together because of this highly selective research initiative. These virtual interactions take on different shapes and forms depending on how they are used and offer examples of emergent hybrid collectives that sustain and promote evolving species of biovalue.

To maintain and exchange the extensive materials offered by SSC, the Simons Foundation developed SFARI Base, which is a central database of clinical and genetic information of all SSC study participants. It contains over 6,000 phenotypic data points for each SSC family and almost 9,000 whole genome sequences, which researchers can explore remotely before requesting samples (SFARI Base nd-a). This digital portal enables scientists to request samples for their research after they sign up and qualify as an approved researcher, a process that requires a lengthy application, Institutional Review Board compliance, and approval by the Simons Foundation. All approved researchers must also agree to the specific use of the SSC materials, which are limited to projects related to “advancing the field of autism and related developmental disorder research” (SFARI nd-a). According to the Researcher Distribution Agreement, approved researchers are also prohibited from using the SSC materials for commercial purposes and required to share all “Researcher Generated Data” within a reasonable time after generation or collection (not to exceed one year) (SFARI nd-a). The scientific practices of open data exchange before publication of results was instituted by autism parent advocates when they developed the first autism genetic database, the Autism Genetic Resource Exchange (Singh 2016).

Establishing an account with SFARI Base is also the starting point for researchers who would like to re-contact SSC families to collect additional data. To qualify, SFARI must approve every scientist before they are put into contact with a liaison to the SSC families. The ability to re-contact SSC families is particularly important for scientists because of the changing dynamics of genomics research that continuously creates new knowledge and categorizations of people based on individual or family genotype and/or phenotype data. Once particular SSC genotypes or phenotypes are identified as worthy of further investigation, additional clinical data or samples of extended family are typically needed. This exchange network generates future use and indefinite value in the SSC by enabling scientists to not only ask new questions of the data but also gain access to additional biomaterials and clinical information needed to test new scientific investigations.

Although re-contacting families was one of the goals in developing the

SSC, initially there were no mechanisms in place to accomplish on-going communication and recruitment for additional studies with SSC families. In 2013, two years after the data collection was completed for the SSC, a digital network of SSC families across North America was established, the Simons Simplex Community@Interactive Autism Network (SSC@IAN). The SSC@IAN was developed to serve as a conduit for connecting SSC families with scientists who wished to collect additional data from SSC families. The 1,500 families who agreed to sign up were willing to be re-contacted by SSC investigators to provide additional blood and medical data when needed. This platform has created an on-going form of exchange between a sub-group of SSC families and scientists who want to collect additional data in order to ask a different set of research questions not originally conceived in the initial data collection. Initial and on-going participating in the SSC is a form of what Mitchell and Waldby (2010) refer to as distributed and extensive forms of clinical labour. Meaning that the small amount of “productive work” is dispersed across many SSC families (e.g., 2,700 families) and extensive through the on-going engagement through both the biomaterials and clinical information already harvested and transformed for scientific production. In the SSC, the clinical labour is also extended through digital networks that enable continued collection of participant data. This adds another dimension of embodied work performed by SSC families.

A third digital network of exchange is a public website that accompanied the SSC@IAN. This was designed as a virtual home for all SSC families (not just those who agreed to be re-contacted) to remain informed about the scientific results derived from their samples, to learn about different families who participated in the SSC, and to access scientific articles on autism (SSC@IAN nd). Additionally, it provides articles on the latest autism research beyond the SSC and webinars on a range of autism topics that would be of interest to North American families who have a child with autism. To some degree the public website offered through SSC@IAN helped to establish a form of biosociality between SSC participating families. The website does this by sharing stories that highlight families who participated in the SSC. The Maclean's, for example, were the first family to sign up to be part of the SSC@IAN and their story emphasizes how participating in SSC “was the best way [they] could help others who are walking the same road.” The story offers a detailed account of participating in the SSC through the words of the mother, who recalled the meltdown her son had when his blood was drawn. Despite the long day and trouble with the blood draw, the mother viewed her participation as scientifically important by stating, how her son's blood sample, “together with those provided by the other SSC families, is part of one of the most important resources in autism research” (SSC@IAN 2011). These sentiments of value and belonging to a community were also central themes among the interviews I conducted with families who participated in the SSC. One mother (SSC parent interview #5) shared with

me that she viewed her family's participation in the SSC as a "moral responsibility" because it would not only help her son but would also benefit the autism community; families like her own who are going through the same struggles. Based on this interview and others, the very act of participating in the study and being involved in SSC@IAN created a collective social benefit for these families because it was not only tied to the value the collection offered the scientific community but also the autism community more broadly. These parents anticipated impactful scientific and social SSC research outcomes that would address major issues facing all autism families such as identifying the genetic cause autism and a clear pathway to helping their children. In this register, participation in the SSC as one parent told me, "benefits everybody, all the way around" (SSC parent interview #4).

In addition to personal accounts of participating in the SSC, the SSC@IAN also provides a list of short reports that highlight studies made possible by SSC families. This serves as another embedded form of biovalue and an alternative way in which biosociality is extended through this virtual exchange network. The introductory paragraph to the list of reports states, "this is autism research made possible by you" (SSC@IAN nd). These reports are based on SSC scientific research and draw on personal stories such as a parent's reflections of the bullying and isolation that occur or the social impairment associated with limited sleep in children with autism. Stories like these and many others are used throughout the reports covering SSC research in the SSC@IAN public website. Sharing these stories unite SSC families beyond their presumably shared genetic mechanisms of autism causation (e.g., CNV mutations) and extend to daily experiences and validation of challenges that families who have children with autism might be undergoing. The use of these narratives also appears to give legitimacy to parent concerns, which in a few cases (e.g., effects of a high fever) are now being investigated using the data available through the SSC. In this register, the knowledge SSC families are able to share with scientists through this virtual exchange highlight new avenues for autism research.

5.5 Selective Non-Flows of Knowledge

A closer analysis of these reports, however, shows that SSC@IAN public website is selective in what is shared with families. Only 19 studies appear in SSC@IAN out of the 78 studies that have been published using the SSC data thus far. According to the SFARI Base website, 197 studies have been approved to use the SSC sample (SFARI Base nd-b). This clearly reflects an imbalance and selective representation of research reported on the SSC@IAN. Not surprisingly, research findings that have much more practical applications for SSC families are typically highlighted (N=13) compared to genetic studies (N=6). For example, studies about aggression and ASD, the stigma and isolation experienced by fami-

lies of children with ASD, or sleep problems linked to autism, are the kinds of research reported to SSC families. The gap in reported studies through SSC@IAN compared to the large number of studies published and approved to use SSC samples is a reflection of the initial priorities of the SSC, which were not necessarily designed to identify practical applications for SSC families and the broader autism community. It also represents what Hoeyer et al. (2017) refer to as strategic ignorance, where some aspects of research are not revealed to research participants because they are expected to dislike them. In the case of SSC, the planned non-flows of information are the exclusion of the majority of studies that are less likely to directly benefit families. It also assumes that families are deficient in the knowledge needed to understand the complexity of genetics research.

Based on this analysis, I do not know why only certain research publications are summarized and made available to families. One interpretation is that the SSC@IAN is strategically filtering what is available to families to give the illusion that the research conducted using the SSC directly benefits SSC families and children with autism more broadly. Another form of nonflows are the recommendations made through these reports to families that are not particularly novel. For example, recommendations made by the study investigators for aggressive behaviour include “the need for interventions to address aggression in children with ASD, and to support families coping with it,” or to address family obesity by focusing “on finding ways to be active together and cope with stress without eating” (SSC@IAN nd). As I discussed above, the knowledge produced and recommendations given are bound within the constraints of the sample, which is largely white, married couples of higher socioeconomic status. Therefore, the practical applications of these findings may only benefit families who are situated within these social locations, since they are more likely to have the time and resources needed to acquire the long-term therapies (e.g., behavioural, speech, occupational) and/or special educational services needed for many children diagnosed with autism. Further, the types of stress, access to healthy food, and coping mechanisms are likely to be very different based on race and social class.

6. Conclusion

This study identified various contours of biovalue established through the development, participation, and use of the Simons Simplex Collection, an autism genetic database designed to investigate specific genetic causes of autism, certain types of families, and characteristics of autism deemed most important for scientific research. Based on this analysis, there are clear representations of scientific, social, and digital forms of biovalue, which are multi-dimensional and co-constitutive of each other;

enabling the exploitation of biovalue in multiple directions with the aid of various technoscientific processes. Scientific biovalue was generated through emergent genomic science that gave rise to the very idea of a simplex family, namely the development and use of genomic technologies that identified small micro-deletions (CNVs) that were associated with certain kinds of autism (Singh 2016). This genomic research finding, marshalled private funders to invest in a new autism genetic database that would test the spontaneous CNV hypothesis. The distinct family forms (simplex families) and detailed collection of clinical characteristics and biological samples created a resource that was valuable for scientists and families alike. The ability for scientists to re-contact families through the SSC@IAN, collect and develop new technoscientific forms of data, and conduct new scientific investigations allows for the expansion of biovalue to travel to new spaces among this emergent assemblage of genomics research. Social biovalue resides in the benefits of participation for SSC families, who not only gain various forms of diagnostic currency, but also have the opportunity to be part of the SSC virtual community. The opportunity to be part of this larger autism community allows families not only to connect with each other, but also offers a linkage to the science that is being produced with their biomaterials. Finally, the digital networks of exchange (SFARI Base and SSC@IAN) creates additional contours of biovalue since it acts as a glue that creates the connectivity and exchange between scientists, SSC families, and the extensive clinical and biological materials.

Within this context, I show how the SSC digital networks mediate between various social and material forms of the sample, updates and transforms biomaterials continuously, and keeps track of the unfolding clinical and genetic profiles of the SSC families. I contend that the productive relation families have with the SSC resides in the ability for scientists to remain in contact with families through SSC@IAN, which enables new signs, symptoms and experiences to continuously be collected, built upon and connected to the knowledge produced from the SSC. As such, the hybrid and multi-dimensional collectives between scientists, SSC families and their clinical and genetic data combined with the emergent digital networks designed to mediate these relationships and data flows generates a resource that can “mined” indefinitely. This positions the SSC to have the potential to generate new biomaterials, genomic knowledge, and research questions in the future, thereby offering promissory or speculative value that holds much promise in genomic science that investigates complex human conditions.

The SSC also enabled new forms of biosociality to form among simplex families whose children potentially have a spontaneous copy number variation ‘causing’ their child’s autism. This collective identity manifests through initial participation and on-going engagements with the SSC. First, the SSC@IAN allowed families to connect with selective knowledge being produced by the SSC using SSC family data, as well as learn about

other families who participated. This sense of belonging to a unique scientific-based autism community was evident from the SSC parents I interviewed who viewed their participation as a way to be part of a research endeavour that will benefit the larger autism community, especially in the future. However, I provide evidence that the knowledge shared on the website was selective to studies that would be most useful for families (e.g., stigma and isolation); studies that were not part of the original design of the SSC, and minimal in both number and value to genetic scientists. Second, the development of the SSC@IAN also created new opportunities for families to remain engaged in the research process especially for those who agreed to be re-contacted by scientists who utilized the SSC for their research. This technosocial arrangement offers the potential for families to identify with the uniqueness of their child's autism, relate to other SSC families, and engage in "artifice of modifying nature and the creation of social forms" (Gibbon and Novas 2008, 4). Undoubtedly, the SSC created new forms of biosociality beyond the shared experiences of raising a child with autism.

This study also uncovers important paradoxes that highlight how the various contours and constraints of biovalue and biosociality work together. First, the scientific biovalue embedded in the selective inclusion criteria and recruitment of families from clinical sites offering autism services in North America created a data set that is largely white and of high socioeconomic status. This is likely a function of who has access to autism services, and therefore eligible to be recruited to participate. It also signals to larger structural inequalities such as limited access to private insurance, living in poverty, and/or racial segregation that creates evident disparities to autism diagnosis and subsequent services (Singh and Bunyak, forthcoming). A second paradox is how these social forms, as well as the different types of biovalue produced, are constituted based on the assumptions built into the SSC. Even though virtual modes of interaction were developed to bring SSC families together, which indeed created new biosocial communities, these collectives are strictly defined based on the priorities deemed most useful for conducting genetics research on autism. Thus, the ideas of autism genetic causation and the biomedical classification of autism shape the kinds of biosocial configurations that coalesce around the SSC. In other words, if a family had two or more children with autism or a family history of autism, they would not be included in these social networks and will also unlikely benefit from the genetic knowledge produced.

A final paradox comes back to the fact that the SSC is an assemblage of people, biospecimen, clinical data, and technologies built on many assumptions about the potential genetic cause of autism and the predominant characteristics associated with its definition. As I have articulated in this paper, while these characteristics created a "Cadillac resource" for autism genetics research, the limitations of the sample based on family structure, clinical characterizations, and representation in terms of race,

social class and sex constrain the types of knowledge produced and the potential future spaces in which this knowledge takes shape and travels. Given that the SSC is the largest autism genetic database of its kind, the knowledge produced will inevitably be a reflection of these assumptions and constraints built into the SSC. This is concerning given the vast amount of research using the SSC to investigate autism causation, treatment and for much of the scientific thrust, an autism cure (e.g., almost 200 studies have been approved to use the SSC). While private philanthropies can bring funding and awareness to important social problems like autism, there is no accountability to create a represented sample, which could potentially limit the expansion of the data production and flows to include research on structural issues faced in more heterogeneous populations experiencing autism.

Given these analytic paradoxes evident in the contours and constraints of biovalue and biosociality, STS scholars engaged with these issues are poised to think about the multi-dimensionality and co-constitutive processes of these “bio” constructs. Further, we must begin to use our critical STS lens to question how these values and subsequent social formations come to be, who they benefit, and how these contours shape and constrain the knowledge produced. Ultimately, these are critical questions of STS and we must pay attention to how heterogeneous values are embedded in artifacts like the SSC and the implications this has for what we come to know about complex human conditions like autism and the primary beneficiaries of this knowledge.

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¹ See Singh (2016) for a detailed account of the problems of previous collections, namely the Autism Genetic Resource Exchange and the Autism Genome Project.

² This is different than a multiplex family that consists of two or more children diagnosed with an ASD.

³ See Singh (2016) for history of the Autism Genetic Resource Exchange and Autism Genome Project.