Prevention of What? Competing Biological Citizenship Claims and the Biopolitics of Autism Prevention

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Competing Biological Citizenship Claims and the Biopolitics of Autism Prevention

A Thesis Presented

by

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ABSTRACT

PREVENTION OF WHAT? COMPETING BIOLOGICAL CITIZENSHIP CLAIMS AND THE BIOPOLITICS OF AUTISM PREVENTION

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In the early 2000s, the idea of an "autism epidemic" spurred State action to expand research into autism's causes and corresponding efforts at prevention, an effort overseen by the Interagency Autism Coordinating Committee (IACC). However, the language of autism prevention in the IACC's Strategic Plan changed dramatically between 2009 and 2017, from the wholesale prevention of autism to prevention of its "most disabling aspects." Through an analysis of IACC meeting transcripts during this timeframe, I trace the process by which this language was changed, with particular attention to the often-conflicting ways in which autistic self-advocates and non-autistic parent advocates framed autism itself. These conflicting conceptions of autism led to conflicting biological citizenship claims regarding the value of prevention, to which the IACC responded by attempting to appease both sides through language without substantially changing its aims. This process highlights the importance of framing in biological citizenship claims, as well as the persistence of the biopower State in asserting the need to regulate the existence of disability in the population.

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CHAPTER I

INTRODUCTION

Modern biopolitics incorporates both top-down action by the State (Foucault 2003) and bottom-up action by individuals motivated to manage their own health and health risks (Rose 2007). These sometimes come together in the phenomenon of activism based around a shared biomedical identity. This has been described as a form of "genetic citizenship" (Heath, Rapp & Taussig, 2002) or "biological citizenship" (Petryna 2002; Rose & Novas 2005), in which groups of people mobilize to demand that their government take action in relation to their particular diagnosis or condition. This often involves calls for greater investment in research related to said condition, in hopes of developing new treatments and cures (Rose & Novas 2005). As Heath, Rapp and Taussig (2002) noted, however, such health-related mobilization can also manifest in opposition to biomedical approaches, as when disability activists challenge purely medical understandings of their impairments, and of disability itself. Both types of biological citizenship claims can be seen at work in discussions of autism.

Michael Orsini (2009:115) explored the application of the biological citizenship concept to both sides of the often-contentious debates within what he called the "autism wars." By this he meant the tensions between non-autistic parent advocates seeking further research into autism's causes and treatment on the one hand, and autistic self-advocates promoting a more positive, less pathologized view of autism on the other. He argued that both groups have made competing biological citizenship claims on the U.S. government, based on significantly different framings of autism and its place in society. He did not, however, outline how these competing claims interact and influence one another when they come into direct contact in a public forum.

One such public forum is the Interagency Autism Coordinating Committee (IACC), in which different perspectives on autism have come into direct conversation with one another. Taking autism prevention as a case study, I explore how competing biological citizenship claims regarding autism have clashed and changed over the course of approximately ten years. Specifically, I have used analysis of the IACC's Strategic Plans, as well as meeting transcripts related to discussions of prevention, to trace the process by which the change in autism prevention language occurred. The results of this analysis highlight the tensions between autistic self-advocates and non-autistic parent advocates, whose arguments related to autism prevention rested on each group's way of framing the condition and its relation to the individual. Like Orsini (2009), I argue that both of these groups were acting as biological citizens while making competing demands for government action based on these divergent frames. Further, I identify efforts by the (State-sponsored) leadership of the committee to appease both sides of the debate over prevention by changing the language regarding what prevention "really" meant while at the same time persisting in the exercise of biopower in an attempt to eliminate the presence of disability.

CHAPTER II

THEORETICAL FRAMEWORK

A. Biopolitics and Biological Citizenship

Foucault (2003:241) proposed that the modern era brought about a shift in State power, in which the traditional power of the sovereign to "take life or let live" was replaced by *biopower*, characterized by "the right to make live and to let die." This biopower operates at the level of the population, rather than the individual; while the sovereign has the power of life or death at the individual level, the biopower State asserts control over the fertility, health, and mortality of the group. It is a normalizing power that seeks to regularize and optimize the population; it constitutes "bioregulation by the State" (Foucault 2003:250). However, as Rabinow and Rose (2006) noted, modern biopower has continued to evolve, and has, in fact, come to encompass individual action as well as that of the State. The authors outlined three key dimensions of biopower that must be present: "truth discourses" made by recognized authorities in relation to the collective life and health of a population, intervention strategies to manage this collective health, and forms of subjectivity in which people identify themselves as part of this discourse and come to "work on themselves" accordingly (Rabinow & Rose 2006:197).

The way in which such biopower comes to be defined, applied and contested can be described as *biopolitics* (Rabinow & Rose 2006). As detailed by Rose (2007) in *The Politics of Life Itself*, modern biopolitics operates through strategies of managing risk. This is often framed in terms of an individual responsibility to identify and mitigate one's own health risks, as well as those of one's offspring. Complementing this "bottom-up" approach to biopower, Rose (2007:73) proposed the idea of a "pastoral" form of biopower, which is positioned to guide citizens in this endeavor through the provision of

expert guidance and services. He emphasized that, rather than being imposed through a top-down mandate, this power is a relational one in which individual choice ultimately prevails—or, to return to the three elements of biopower identified by Rabinow and Rose (2006:197), the subjective sense of the need for individuals to "work on themselves" is influenced by the expert "truth discourses" and available interventions offered.

The State is not the only source of this pastoral power, but it is still frequently called upon to provide expert guidance and fund services related to life and health. In fact, in their critique of work by Rabinow and Rose, Raman and Tutton (2010) emphasized the role of the State by suggesting that rather than eliminating the earlier focus on the population in favor of the individual, modern biopower combines the two in ways that can become quite complicated. To draw examples from the current discussion of autism and the IACC, the collection and use of population-level statistics, such as autism prevalence numbers, maintain a focus on the population level, as do State funding and implementation of research programs. Thus, even when considering the State as primarily exercising a form of pastoral power guiding individual choice, there is still the question of *whose* expertise, and *what* truth discourses, are supported by institutional and cultural authorities (Raman & Tutton 2010).

This complexity also becomes evident in manifestations of the "bottom-up" form of biopower emphasized by Rose (2007). In many cases, individuals do not mobilize on their own, but instead come together in "biosocial" (Rabinow 1996) groupings, in which people form collectivities based on shared biological traits. When biosocial groups begin to call upon the State for action related to such shared traits, they act as "biological

citizens" (Petryna 2002; Rose & Novas 2005) asserting the need for attention to be paid to their particular (biologically-defined) group.

This concept of biological citizenship has been explored in the context of autism in at least two senses. As Michael Orsini (2009:115) explained, "I use the term 'autism movement' to distinguish activists or advocates more interested in pressing for policy change around the treatment for autism and concern with its causes, versus the term 'autistic movement,' which normally refers to the efforts of activists to create a positive identity for autistic people using, albeit not exclusively, a disability rights frame." He went on to clarify that these two groups are not always divided along autistic/non-autistic lines, nor along parent/child lines (Orsini 2009), but as Rottier and Gernsbacher (2020:156) noted, the "discordant priorities" between non-autistic parent advocates and autistic self-advocates have a long history. Both forms of advocacy rest on the identification of participants as biological citizens with legitimate claims to government attention (Orsini 2009), but those claims frequently rest on very different ways of framing autism itself.

B. Divergent Frames and Biological Citizenship Conflicts

Goffman (1974:8) described frames as the subjective interpretations by which people answer the question, "What is it that's going on here?" As Benford and Snow (2000) pointed out, the action of framing is a form of meaning-making, and one that is actively employed by social movements as they seek not only to define a problem in society, but also to mobilize support for their proposed solution(s) to it. Because social movements are generally attempting to change some existing aspect of society, their framing efforts often challenge mainstream interpretations of reality, and therefore may

face challenges from both inside and outside the movement, including "counterframing" by those who oppose them (Benford & Snow 2000:625-6).

In disability studies, approaches to disability framing often contrast the medical model, which focuses on individual impairment in a medicalized fashion, with the social model, which focuses on the role of structural and environmental factors in producing disability (Shakespeare 2017). While, as Shakespeare (2017) pointed out, a purely social model approach may be criticized for ignoring the (often substantial) difficulties created by individual impairments, social model perspectives bring into view the role of exclusion, discrimination, and structural barriers in creating the experience of disability. As Shakespeare (2017:200) put it, "In practice, it is the interaction of individual bodies and social environments which produce disability." These two disability frames have played significant roles in the evolution of attitudes toward autism.

In the United States, the initial identification of autism came from Leo Kanner, who conceived of autism as a rare and highly debilitating disorder, as opposed to the broader spectrum it is viewed as today (Eyal et al. 2010). The framing of autism by the most prominent parent-led advocacy organizations began as a form of counterframing as parents pushed back against early assertions that autism was caused by a cold and emotionless parenting style, particularly by mothers who were disparagingly described as "emotional refrigerators" (Eyal 2013:868). Successful counterframing by early parent advocacy groups led to a shift away from this parent-blaming approach and toward one in which parents came to be seen as autism experts in their own right, based on their knowledge of their autistic children (Eyal 2010). As Eyal et al. (2010) described it, however, part of this process involved counterframing autism itself into the *cause* of

harm to the family, rather than a *result* of harm done by the parent(s). This shift in framing likely contributed to the tendency, documented by McGuire (2012), for advocacy organizations led by parents and professionals to treat autism as something separate from the at-risk child, and indeed as a growing epidemic against which action was necessary.

Of course, while this way of framing autism may have begun as a form of counterframing, it remained firmly within a medical-model approach, and its alignment with the pre-existing view of autism as a disorder arguably allowed this counterframe to become the dominant frame through which autism is viewed. And the specific framing of autism diagnoses as an epidemic also positions it as a public health crisis requiring State intervention and, indeed, prevention. Further, an epidemic implies the spread of a disease, and viewing autism as a disease positions it as something dangerous, invasive, and harmful to the individual (Broderick 2010). Elaborating on the construction of autism as a disease, Nadesan (2005) argued that biomedical approaches tend to view diseases as independent entities, separable (at least in theory) from those they afflict; autism has been no exception. By framing autism as an epidemic, "autism is metaphorically constituted as an invasion by a diseased alien entity, to which parents or society must respond by engagement in militaristic intervention operations" (Broderick 2010:256). In some communities, autism is seen as a "Western disease" (Decouteau 2021:4) brought on by the particularities of the Western (and perhaps specifically North American) lifestyle. This framing of autism emphasizes potential environmental causes, positioning autism as something acquired through environmental exposure, and therefore potentially preventable and/or curable through remediation of that exposure (Decouteau 2021).

The framing of autism by self-advocates, in contrast, has tended to incorporate elements of the social model, emphasizing the role of social exclusion and lack of support in addition to the intrinsically disabling aspects of autistic experience (Yergeau 2018:108). Importantly, many self-advocates position autism as something intrinsic to the self, and often see it as a positive, or at least neutral, difference despite its difficulties (Kapp et al. 2013). The neurodiversity perspective, in particular, posits autism (among other neurobiological differences) as part of the natural diversity of human minds, though one that is often disabling within a society not designed for it (Kapp 2020). Further, self-advocates have insisted that their perspectives on autism deserve to be heard, and that autistic people should be part of any discussion related to autism (Rottier & Gernsbacher 2020).

If both non-autistic parent advocates and autistic self-advocates have come to act as biological citizens in relation to autism (Orsini 2009), how do these divergent frames influence their demands for government action? Rose and Novas (2005) noted that the formation of biosocial groups, and the assertion of biological citizenship, often centers on the group's hope for a better future for those sharing their biological traits. "Contemporary biological citizenship, that is to say, is a hopeful domain of activity, one that depends upon and intensifies the hope that the science of the present will bring about cures or treatments in the near future" (Rose & Novas 2005:24). But as already noted, not all biological citizens agree that the elimination of their particular biological identity is their best hope. Some challenge a purely medicalized approach to requests for care, as when disabled activists fight for inclusion and accessible environments in addition to appropriate health care (Heath, Rapp & Taussig 2002). And Kapp et al. (2013) found that

autistic people who took a positive view of autism overall did not deny its more disabling aspects, and were generally in favor of taking steps to ameliorate them—but they also tended to be against the idea of a wholesale cure. (Non-autistic parents in their study, meanwhile, were more likely to support research into causation and cures.) Likewise, it would not be surprising for people who view autism as an intrinsic part of themselves (Kapp et al. 2013) to be alarmed at the idea of preventing autism; from this perspective, this inherently implies the prevention of autistic people like themselves. As will be seen in the discussions of autism prevention within the IACC, some parent advocates indeed position the prevention and/or cure of autism as the primary hope of families like theirs, but many autistic self-advocates decry this focus as a form of eugenics.

The logic of eugenics has historically targeted both disabled and racialized people based on hierarchies of value and notions of biological inferiority (Mitchell & Snyder 2003). Disabled people, in particular, have frequently been constructed as "social burdens" and economic drains on society (Selden 2000:238). The need to reduce the emotional and economic burden placed on society and/or families, as well as to alleviate presumed suffering, were both invoked by the Nazis to justify their eugenics program (Mitchell & Snyder 2003), which borrowed heavily from the U.S. eugenics movement (Black 2003). And while that historical eugenics movement came to be discredited—and some, like Rose (2007) argue that the word no longer applies in the absence of top-down mandates—the modern science of genetics shares roots with eugenics, and both share similar logics of finding and fixing hereditary "defects" (Snyder & Mitchell 2002:103).

Whether or not the word "eugenics" is applied, biopolitics necessarily rests on judgments made about the value of different forms of human life (Rose 2007). Within the

biopolitics of autism, discussions of prevention are particularly fraught with judgments about the value of autistic life, and what it means to prevent it. The autism advocacy movement has presented the parents of autistic people as biological citizens with a stake in these discussions by virtue of their genetic relationships to, and claims of speaking for, their children. (It is important to note, following Decouteau (2021), that this has primarily been an effort by wealthy white parents, and that not all parents view their children's autism as the result of shared genetics.) By challenging the assumptions and value judgments surrounding the concept of prevention, autistic self-advocates can be seen as making a competing claim of biological citizenship on their own behalf.

As a site for study, the IACC offers an opportunity to study not only how conflicting frames interact with one another, but how the biopower State responds to them. For example, Decouteau and Daniel (2020) studied the process by which the IACC maintained a biomedical focus on autism as primarily genomic in origin by absorbing challenges from laypeople and alternative treatment movements that position autism as environmentally caused. They described this process as "subsumptive orthodoxy" (Decouteau & Daniel 2020:3), in which the dominant biomedical perspective incorporated a portion of the environmental-cause argument by redefining "environment" as the environment of the fetus *in utero*, rather than environmental risks posed to the young child, such as vaccines, pollution, etc. This subsumptive orthodoxy functioned to co-opt the message of the alternative treatment social movement, allowing the biomedical/genomic understanding of autism to maintain its hegemony in the field.

Viewed as an example of framing and counterframing by social movements (Benford & Snow 2000), this process of subsumptive orthodoxy can be seen as an

attempt by the committee's government leadership to appease both sides of a debate over the causes of autism. Rather than fully adjudicating between competing frames, the IACC engaged in wordsmithing the definition of "environment" to give the appearance of incorporating divergent perspectives while maintaining its focus on genomic causes as the dominant explanation (Decouteau & Daniel 2020).

In that study, the authors briefly discussed the changes in prevention language that I address in my analysis, not as a similar example of subsumptive orthodoxy, but rather as a "counter case" in which "lay/patient mobilization has indeed had a profound impact on the debates, policy, and capital investment driven by the IACC" (Decouteau & Daniel 2020:22). However, I argue that while the discourse around prevention certainly changed in response to challenges from self-advocates, the process was not a straightforward case of public mobilization. Instead, it resulted from a clash between two intertwined forms of biological citizenship resting on conflicting frames regarding autism. Further, I argue that the State's response to this conflict was not to adjudicate between these frames, but rather to engage again in subsumptive orthodoxy, in which the IACC leadership attempted to appease both sides by changing its language but not the ultimate aim of using biopower to regulate the existence of disability in the population.

CHAPTER III

BACKGROUND

A. The Autism "Epidemic" and the Creation of the IACC

The definition of autism has expanded significantly since its early characterizations, from a rare disorder to a broader "spectrum" condition encompassing a range of presentations and diagnostic criteria (Eyal et al. 2010). These changing definitions have been accompanied by significant increases in autism diagnoses over the past few decades, a phenomenon sometimes given the contested label of an "autism epidemic" (Gernsbacher, Dawson & Goldsmith 2005). This framing of autism as an epidemic has led to an increase in U.S. government efforts to mobilize resources to "combat" autism (U.S. Congress 2006), including the formation of the Interagency Autism Coordinating Committee (IACC).

The IACC is a federal government advisory committee reporting to the Secretary of Health and Human Services (IACC n.d.a.). It was initially authorized by the Children's Health Act of 2000 (U.S. Congress 2000), then reauthorized and expanded by the more aggressively named Combating Autism Act of 2006 (U.S. Congress 2006). Contemporaneous reporting approvingly dubbed the latter the "U.S. government's 'war on autism'" (McGuire 2016:146), and in the first meeting of the IACC in 2001, its chair began the session by saying, "Indeed, one of the goals of this Committee…is to really think about how we can most constructively move forward in the goal, which is research and, ultimately, *success against autism*" (IACC 2001:9; emphasis added). In pursuit of this goal, the committee's mandate has included the directive to advise on issues of

research related to autism's causes and corresponding efforts at prevention (U.S. Congress 2006:7).

While the committee was clearly created with the "disease" framing of autism in mind, the IACC provides a potent site for illuminating the conflict between different frames. This is particularly true given how its composition changed over the years examined in this study. The original makeup of the IACC consisted of representatives of government agencies deemed relevant to autism; these "Federal" members have largely represented government agencies concerned with public health, such as the National Institutes of Health and Mental Health, the Centers for Disease Control and Prevention, and the Department of Health and Human Services (IACC n.d.b.). Initially, parents and guardians of autistic people could also be appointed to the committee, though this was not required (U.S. Congress 2000). When the committee was next reauthorized, it was mandated to include at least one person with an autism diagnosis, and at least one parent or guardian (U.S. Congress 2006). These "Public" members have frequently represented autism advocacy organizations such as Autism Speaks, The Coalition for SafeMinds, and the Autism Society of America (IACC n.d.b.), which are themselves dominated by the concerns of parents and families (McGuire 2016). Although multiple parent advocates were present on the committee starting in 2001 (IACC 2001), the first autistic member joined the committee in 2007 (IACC n.d.c.), and it was not until 2010 that the committee's roster included more than one member with an autism diagnosis (IACC n.d.d.). That year, there were two autistic members and six non-autistic parent advocates among a total of twenty-two committee members (IACC n.d.d.).

Although both self-advocates and parent advocates were numerical minorities on the committee, much of the analysis that follows centers on opposing beliefs about autism and prevention arising from these two constituencies. In addition to discussion among members, however, the committee's general meetings included calls for public comment, which drew attention from both non-autistic parent advocates and autistic self-advocates. I have included some of these in my analysis, particularly where they resulted in further discussion within the committee.

B. Autism Prevention in the Strategic Plan, 2009 - 2017

The Strategic Plan is one of the publications the IACC is mandated to produce and update on a regular basis. It is intended to encapsulate the committee's advice regarding the direction and funding of autism research and services by federal agencies as well as private organizations (IACC 2017b). The first Strategic Plan was published in 2009, and it was updated annually for the following four years. There was then a gap between 2013 and 2017, then a smaller gap before the most recent update was published in 2019, for a total of six updates since the original. Because the 2019 update used a different organizing structure than previous updates, I have focused on changes in the language of prevention between the 2009 Strategic Plan and the 2016-2017 update, and related discussions in the transcripts.

These Strategic Plans were structured around a series of questions intended to address several areas of inquiry, with the third question raising the issue of prevention (IACC 2009a). Originally, Question 3 read: "What Caused This To Happen and Can It

Be Prevented?" (IACC 2009a:2).[1] In the 2016-2017 update, however, this question was changed to read, "What Causes ASD, and Can *Disabling Aspects* of ASD Be Prevented or Preempted?" (IACC 2017b:iii; emphasis added). This shift from preventing "it" (i.e., autism) to preventing its "disabling aspects" marks the change that is the central focus of this paper.

This change in language was also reflected elsewhere in the report. In addition to Question 3, early Strategic Plans (including the original 2009 publication and its 2010 and 2011 updates) also discussed prevention as a "crosscutting theme" in the introduction to the document. That description read, in part: "It is critical for research to identify the methods and approaches that can be used to prevent the challenges and disabilities of ASD. Additionally, if one views ASD as a biological disorder triggered in genetically susceptible people by environmental factors, then prevention can include prevention of new cases of ASD through the identification and elimination of environmental causes….Having sound research on the risk factors and the environmental triggers for ASD ultimately may allow us to achieve the goal of prevention: preventing the development of the disorder in some people at risk or reducing the degree of severity in those affected" (IACC 2009a:4-5).

While the crosscutting theme was removed from the Plan after 2011, the 2016-2017 update contained a strikingly different description of prevention efforts: "A few years ago, scientists saw autism as a disorder to be detected, treated, prevented, and cured. The majority of research was directed at understanding the genetic and biological

[1] In the 2009 and 2010 Strategic Plans, the phrasing, "Can It Be Prevented" was used in the Table of Contents, while "Can This Be Prevented" was used in the body of the text. The body text was changed in subsequent updates to match the Table of Contents.

foundations of autism, and toward early detection and intervention. Today, our understanding of autism is more nuanced….Most importantly, individuals on the autism spectrum have become leading voices in the conversation about autism, spurring acknowledgment of the unique qualities that people on the autism spectrum contribute to society and promoting self-direction, awareness, acceptance, and inclusion as important societal goals" (IACC 2017b:vi).

This explanation of the shift in language makes explicit reference not only to the influence of autistic perspectives, but also to the role of framing. The reference to the neurodiversity movement is essentially a nod to the counterframing of autism employed by many autistic self-advocates, which challenges the purely medical-model framing of autism as a disorder, disease, and/or epidemic. However, it is also important to note that the updated language maintains a focus on preventing autism's "most disabling features," highlighting the continued assertion by the State of the need for disability to be managed and, if possible, eliminated. Further, the contents of this section did not change as dramatically as its introduction would suggest. My analysis will illuminate how this (partial) shift in framing was accomplished, as well as its limitations.

CHAPTER IV

DATA AND METHODS

As previously noted, IACC meetings offer a rich site for observing the interaction between different ways of framing autism. As a public forum, the committee invites different perspectives from both members and the public at large, and as a government entity, its recommendations have real-world consequences. IACC meeting transcripts provide multiple interactions in which business as usual—i.e., the medical-model framing of autism as an epidemic requiring State intervention and prevention—was interrupted by challenges from autistic self-advocates taking a more social-model perspective on autism. As such, its activities offer the possibility for moments of positive contingency, in which a small group of people have the opportunity to affect outcomes for a much larger group through the resolution of uncertainty (Lara-Millán, Sargent & Kim 2020).

The IACC website (IACC n.d.a.) provides a great deal of documentation regarding the committee, including its purpose, mandated publications, membership rosters, and meeting minutes and transcripts from 2001 to the present. Committee meetings are divided into full committee meetings, subcommittee meetings, and working group meetings, as well as occasional one-time workshops. For this project, I conducted an in-depth analysis of the transcripts of full committee meetings and working groups focused on the Strategic Plan.

Full committee meetings occurred on an approximately quarterly schedule, providing thirty-nine meeting transcripts between March 2008 and January 2017. Full meetings typically lasted an entire workday, from 9 AM until 4 or 5 PM, and included

discussions of multiple topics related to autism. In addition to full committee meetings, there were eight working group meetings to plan the initial 2009 Strategic Plan, six working group meetings for the 2011 Strategic Plan update, and three working group meetings specifically focused on Question 3 in the 2016-2017 Strategic Plan update. In all, these transcripts totaled over 14,600 pages of text.

The sheer volume of transcript materials necessitated a targeted approach to reviewing discussions of prevention. My approach was similar to Skocpol's (1984:383) description of "targeted primary investigations," in which secondary sources are given context and grounding by specifically-selected primary sources. In this case, the Strategic Plans can be viewed as secondary sources, in that they are more refined documents whose contents derived from the discussions represented by my primary references, the meeting transcripts themselves. Having identified the change in language related to prevention in the Strategic Plans, I focused specifically on transcripts where this was discussed.

For my analysis, I used MaxQDA Plus 2022 to organize and review materials downloaded from the IACC website. After my initial identification of the previously-described changes in the language of prevention across Strategic Plan updates, I imported all of the full committee meeting transcripts, as well as transcripts from the working groups focused on the Strategic Plan. I then searched for and reviewed all discussions of "prevention" across all of these transcripts. This targeted review highlighted the role of both parent advocates and self-advocates in shaping the discussion, as well as the response from the government in the form of the committee's chairman at the time. With this focus in mind, frequent participants in this conversation are identified by name, while

others are identified only by their role on the committee. In my analysis, I take a largely chronological view of the evolution of this discussion, and analyze how the language in the Strategic Plan came to be changed.

CHAPTER V

THE CHANGING LANGUAGE OF PREVENTION

A. Different Frames, Different Goals

As a baseline to establish the initial understanding of what "prevention" referred to, a 2008 discussion in the working group focused on drafting the first Strategic Plan made it clear that "prevention" was intended to mean the prevention of autism, or at least "full-blown" autism. As one participant (representing Autism Speaks) put it, "So there was an interest in the concept of prevention, that we might be able to intervene in autism before the full-blown syndrome is present, and therefore alter the developmental trajectory" (IACC 2008a:39-40). Similarly, Alison Tepper Singer, a parent advocate formerly with Autism Speaks and now representing the Autism Science Foundation, also laid out the issue quite clearly during that same meeting. After outlining the initial concerns parents have about finding services for their child, she added, "And then I think after our children are settled a little bit, we start to think about how can we work to prevent this from happening to other children, including any subsequent children that we may have or our grandchildren" (IACC 2008a:105).

Lyn Redwood, another parent advocate from the anti-vaccination Coalition for SafeMinds, also made things clear in a full committee meeting the following month, saying first that "another area I see missing on there is 'How do I prevent this from happening?' I see where it starts from the assumption that the child has autism, and there is not much there to [say] how do I prevent autism from happening to begin with" (IACC 2008b:89). She later followed up with the observation, "I know as a parent when you have a child and you are considering having another, that is the first question on your

mind" (IACC 2008b:90), and later, "I think if we are talking about treatment we should also talk just as strongly about prevention. Then we won't have to deal with the adult services" (IACC 2008b:91). Another Public member, a clinician offering diagnostic services, replied, "I deal with the families that are asking me that same question. Is this child I'm pregnant with going to have autism. I think that it is like the elephant in the room here….I really don't feel that we know what the cause of this epidemic, if you will, is. How can we prevent something if we don't know what is causing it" (IACC 2008b:91-92).

From the above, it appeared to be unproblematically accepted that preventing autism was valued as a goal, and this was seen as particularly important for families worrying about whether to have another child (or presumably to continue a pregnancy) if that child is likely to be autistic. Note that the goal of prevention was also closely linked with the search for autism's causes, as well as the idea of a growing epidemic. These concerns reflect the framing of autism as a public health problem, for which parents and families—acting as biological citizens—demanded action from the State. Further, at this stage there does not seem to have been a need to explain *why* autism needed to be prevented; it was straightforwardly assumed to be a threat to be addressed, suggesting that parent advocate and government ways of framing autism were aligned.

However, it is instructive to note what happened later in that same 2008 meeting when the one autistic committee member at the time, Dr. Stephen Shore, challenged this focus on prevention. He did so both by emphasizing the need to improve the quality of life for existing autistic people, and by pointing out that in addition to challenges, autism also encompasses strengths that would be lost if autism were eliminated (IACC

2008b:109-110). Both arguments highlighted the value of individual autistic lives, first by positioning them as deserving of support for existing difficulties, and second by countering the framing of autism as strictly a burden. In response, Lyn Redwood justified the goal of prevention by emphasizing the need to reduce suffering, saying, "There are families out there who have children that are just absolutely miserable. They don't sleep at night. They have diarrhea. They pull their hair out. They injure themselves. Those families talk about prevention because they want to prevent that from happening to anybody else. But then you have people on the spectrum that are very high functioning. So, how do you meet the needs for such a diverse community." (IACC 2008b:123)

Note that this statement uses two tactics to deflect criticism of the idea of prevention, both related to how autism is framed. First, it conflates co-occurring conditions such as sleep disorders and GI issues with autism itself, indeed treating them as symptoms of autism when they were not part of its clinical definition (American Psychiatric Association 2000). Second, while she does mention the diversity within autism, she reduces that diversity to high functioning and low functioning people, with the implication that the former are not disabled while the latter are "miserable." Both of these rhetorical moves point toward fundamental disagreements over what autism "is," which reflect the differences in framing noted earlier.

After Redwood's defense of the need for prevention, a Federal committee member offered the following redefinition of its aim: "*I tend to think of prevention as not prevent the whole person disorder but how do you prevent the disabling symptoms*….Here you still have that person and you are trying to get rid of those things that are causing the difficulty: the GI, the hair pulling, the not being able to speak, but not

lose the unique qualities that are positive aspects of many people with autism. I would just encourage us to think of prevention in terms of disabling symptoms" (IACC 2008b:123-124; emphasis added).

This represents an important shift away from "preventing autism" to preventing its (broadly-defined) "disabling symptoms." This redefinition began to recur quite often, particularly in 2008 and 2009 as challenges to prevention were repeatedly raised, primarily by autistic people who were either committee members or offering public comments. Note, however, that this redefined version of "prevention" still seeks to define, surveil, and eliminate the appearance of disability in order to improve and normalize (Foucault 1978) the population. It also absorbs those challenges to prevention into a persistent medical-model framing by shifting away from autism as a "whole person disorder" to framing it as something with individual symptoms that could potentially be cured.

B. Self-Advocates Raise Ethical Challenges to Prevention

While some, like Dr. Shore, questioned the focus on prevention as a distraction from improving the lives of existing autistic people, other autistic commenters questioned it on explicitly ethical grounds. For example, the following public comment was offered during the same meeting in March of 2008 by Ari Ne'eman of the Autistic Self-Advocacy Network: "Finally, genetic research surrounding prenatal tests for the autism spectrum is also a grave concern….There is evidence that such tests will and are leading to the use of selective abortion to engage in eugenics against the developmentally disabled. It should be noted that approximately 90 percent of fetuses that test positive for Down's [sic] syndrome are aborted. While a prenatal test for the autism spectrum is

significantly more complex to develop, once it is in existence the current climate of fear makes a similar result likely. We hold no position on the abortion debate in general, but we are deeply concerned by the emergence of eugenics in American society" (IACC 2008b:219-220).

This direct reference to eugenics in relation to prevention marked a notable escalation in the criticisms being mounted. The parallel case of Down syndrome was one that would be brought up repeatedly by autistic critics of prevention, including Ne'eman himself when he later served on the committee. Having a specific, real-world case highlighting the ramifications of research into causation and prevention of another developmental disability was a potent reminder that concerns about eugenics were not unfounded or merely hypothetical. This was also a clear example of autistic biological citizenship being asserted, centered on the rights of autistic people to exist.

Other voices, however, were reinforcing the biological citizenship claims of parent advocates over those of autistic self-advocates. In contrast to concerns from autistic people about both the opportunity costs of focusing on prevention over support services for existing people and the eugenicist flavor of prevention efforts, other public comments around this time urged the committee to do *more* in the area of prevention, often with a focus on vaccines and other, often-disputed connections with environmental factors (IACC 2008c). Committee discussions of research into environmental factors also tended to include references to prevention and to reversing the upward trend of autism prevalence numbers (i.e., ending the "autism epidemic"), as will be seen below. The dissonance between maintaining a goal of reducing the prevalence of autism diagnoses and the idea that prevention was *really* aimed at preventing the most disabling features of

autism, not eliminating autism itself, continued to plague committee discussions of the issue.

Ultimately, the result of this discussion was the addition of the "crosscutting theme" of prevention to the 2009 document, which was seen as a way to move past controversies about language, and at least avoid the appearance of endorsing eugenics. As one parent advocate put it, "Prevention is a very, very touchy subject. We are having this debate here and it shows that there is not full clarity in what its meaning is and if in any way it can be interpreted as devaluing people with autism, then I say that we probably should leave it out because we'll have people rejecting our work just by looking at our values and our mission statement based on what could be perceived as just semantical but it's very important to them." (IACC 2008c:49-50) More clarity regarding what was *meant* by prevention, then, was seen as the answer to the objections autistic self-advocates were raising, but this did not address differences in framing.

C. Appeasement Attempts Lead to Ambivalent Framing

The question of what was meant by prevention continued to be discussed during the remainder of 2008 and into 2009, but clarity remained elusive. During the November 2009 full committee meeting, the issue was introduced with repeated insistence that "prevention really means to enhance quality of life" (IACC 2009b:103), and that, "When the term 'prevention' was to be used specifically, was to address amelioration of comorbid medical conditions that might be associated with ASD" (IACC 2009b:190). However, Chairman Thomas Insel pointed out that this view of prevention didn't align with the goal of discovering environmental risk factors and susceptibility, or the related

aspiration to be “able to prevent ASD by making sure people don't get exposed to something that could cause it” (IACC 2009b:191).

In addition to noting the ambiguity in the language of prevention, Insel’s comment highlighted the fact that research into causation carried an implicit goal of prevention. So did research into costs. In July of 2010, the committee heard a presentation from Dr. Michael Ganz from the Harvard School of Public Health (IACC 2010a:12), focused on the societal costs of autism. In his presentation, he explicitly linked the accounting of costs with the benefits of prevention, saying that “to understand the cost or the burden of autism or any condition now is in some sense the value of prevention. I mean, if we can prevent or ameliorate a condition, their current cost is equal to the value of prevention” (IACC 2010a:17).

After his presentation, Ari Ne’eman from ASAN, now the second autistic member of the committee, called out this connection between such a cost analysis and the benefits of prevention. He asked, “Isn't what you are saying here essentially these people are expensive, we have calculated exactly how expensive they are, now let's save that money by preventing them from existing? How would you distinguish your views from the views of say, the eugenics movement of the 20th century, which did a very similar thing?” (IACC 2010a:45-46).

As might be expected, this question was not received well, with Ganz describing it as “ridiculous” (IACC 2010a:46). He then explained that “the point of this work is to point out the lost opportunity costs associated with people who have a health condition that hopefully can be prevented, and I am not meaning that the folks should be prevented from being born. I mean that they should be prevented from experiencing that condition”

(IACC 2010a:46), which he then compared to such things as depression, cancer, and bladder conditions. As noted earlier, this relies on the framing of autism as a disease, rather than an intrinsic part of an individual's personhood. In contrast, Ne'eman again brought up the parallel example of Down syndrome, noting that prenatal testing for Down syndrome has led to a high percentage of fetuses with the condition being aborted. When asked if that, too, was an example of the financial benefits of prevention, Ganz replied that, "I think that reading too much into this from an ethical standpoint, certainly people are going to do that, but that's not what I set out to do. I set out to do an accounting exercise" (IACC 2010a:47-48). Both Dr. Ganz and Chairman Insel ultimately defended the cost analysis as being just "the numbers" (IACC 2010a:50).

Ne'eman's questions again highlighted the divergent frames through which different parties viewed autism, particularly the question of whether autism should be seen as intrinsic to a person or as a potentially curable disease. They also challenged a purely medical-model approach of accounting for costs without regard to social-model considerations, such as the values and political choices that determine what is counted in "the numbers" and what is not. For example, Ne'eman pointed out that it is a choice to attribute the cost of high rates of unemployment among autistic people to their autism, versus attributing it to a lack of workplace supports or to societal ableism (IACC 2010a). This challenge repositioned autistic people as legitimate biological citizens with needs that can be met, rather than as burdens to be managed.

The question of what was really meant by "prevention" was raised again in a full committee meeting in December of 2010. Ari Ne'eman pointed out that Question 3 of the Strategic Plan, "What caused this to happen, and how can it be prevented?" was not in

line with earlier discussions of prevention as being focused on the challenges of autism, rather than autism itself, and suggested that the question be edited down to just "What caused this to happen?" (IACC 2010b:89). Other committee members argued that *some* focus on prevention was legally part of their mandate, and that the crosscutting theme in the introduction had previously explained what they meant by "prevention." Ne'eman acknowledged this, but again pointed out the conflict between the discussion in the crosscutting theme and Question 3, suggesting instead that "in the spirit of matching this title most closely to the crosscutting theme language that we have, I would suggest the language read: What Caused This To Happen And Can Challenges Be Prevented?" (IACC 2010b:96). There was then a vote on changing the title, which failed.

This failure reflects the ongoing ambivalence within the committee toward redefining prevention to mean the prevention of the challenges and disabilities related to autism versus the existence of autism itself. Given how often the discourse around prevention kept shifting between those two perspectives, there were clearly many committee members for whom "prevention" still meant preventing autism, as reflected in the decision to maintain the question's wording to include "and how can *it* be prevented" (IACC 2010b:100; emphasis added). And as committee members had pointed out, this was part of its legal mandate—a mandate resting on State-level implementation of biopower in response to a perceived autism epidemic.

This mandate for State action on prevention occasionally brought the difficulty of accommodating such divergent frames into stark relief. In 2012, for example, Chairman Insel tried to mollify both sides of the prevention issue by referencing the "diversity of the autism community" (IACC 2012:157) and noting some of the differences in the

framing of autism by different groups. “There are people in this community who think of autism exclusively as an illness to be cured and prevented, some who think of it as a disability where the issues are all around social justice and civil rights, and some who think of it as an injury. And there, the issues are very different as well and have to do with everything from compensation to possibilities of future prevention. All of those need to be at the table. We need to be able to talk about all of them, and we need to find some common ground because where we have been most effective in the past is not as a debate society, but as a Committee or as a community that comes together and identifies those things that we can all agree about, that we want to make either by accelerating progress or by pushing the envelope in terms of awareness. We want to make things happen” (IACC 2012:157-158).

However, this insistence on “mak[ing] things happen” elides important differences not only in what actions different sectors of the community think are appropriate—or even ethical—to pursue, but also in what each sector thinks autism *is*. Finding “common ground” on which to take action would require addressing these different understandings of autism, because these lie at the heart of disagreements over what should be done about it. Chairman Insel even called attention to these different meanings of autism, but at the same time seemed impatient at the idea of the committee becoming a “debate society.” He appeared unwilling to entertain these framing disagreements in any depth, and instead sought to bring them all under the umbrella of the committee’s mandate to take action.

Due to this unwillingness to adjudicate between different frames, the insistence that prevention “really” meant preventing the more disabling aspects of autism, and/or

co-occurring conditions, was sometimes contradicted by the committee's leadership. In the April 2014 full committee meeting, for example, a number of public commenters excoriated the committee for not doing enough to prevent autism and its associated costs (IACC 2014). Chairman Insel summarized such comments by saying, "I guess what I came away with most of all from many of the people we heard from was just the frustration and anger that we haven't delivered as a Committee…that we have failed -- as people said -- failed to prevent a single case, failed to provide a single cure….And so people have every reason to feel frustrated, especially as they see the numbers go up and not down. So we're not bending the curve. The curve is actually going in the wrong direction" (IACC 2014:207-208).

D. Changing Language, Unchanging Aims

Despite this continued ambiguity, it was in the next Strategic Plan update that new language was used to move away from a focus on preventing autism entirely and toward prevention of individual difficulties and co-occurring conditions. In the working group focused on updating Question 3, there was a great deal of discussion about how to frame the issue, again noting the "polarization" (IACC 2016a:12) within the community related to the validity of prevention as a goal. One committee member characterized the disagreement as being about prevention of the "big 'It'" (IACC 2016a:16) of autism rather than specific challenges or behaviors to improve quality of life. (This was in reference to the word "It" in the phrasing of Question 3, "Can It Be Prevented?") Another speaker agreed, saying that "We're not really talking about an "It", we're talking about a continuum of impairment and then the prevention question becomes one of sort of shifting that distribution" (IACC 2016a:19).

By positing a difference between the "it" of autism and specific challenges, and further highlighting that those challenges exist along a continuum, the conflation of autism with other co-occurring medical conditions began to break apart. And in the third meeting of the Question 3 working group in 2016, we can finally see the wording of the question change. The working group acknowledged that the retention of the word "It" in Question 3 no longer reflected the way the committee was discussing prevention, nor how it was presented earlier in the Strategic Plan. At one point it was acknowledged that the original intention was indeed the prevention of autism, but the proposal was then made to change the wording to "can disability be prevented" and to take that to the full committee for confirmation (IACC 2016b:39). The final wording, updated to "what causes ASD and can disabling aspects of ASD be prevented or preempted," was then introduced at the next full committee meeting in January of 2017 (IACC 2017a:119), and the new language was accepted with very little comment.

The 2016-2017 Strategic Plan itself offered the following reason for the change in the wording of Question 3: "The title to this chapter has changed (from "What caused this to happen and can it be prevented?") *because the neurodiversity movement has had a great impact* on the IACC and on the premises of the Strategic Plan enterprise. *It is fully appreciated now that some features of autism should not necessarily be targets for prevention. As discussed above, it is the most disabling features of autism that are now the major targets of prevention or preemption*….There is clearly an increased sensitivity to any procedure or practice that would be directed at preventing the totality of autism, and this is reflected in the emphasis of this chapter**"** (IACC 2017b:30; emphasis added).

However, it is important to note that while the wording of the question was changed, the contents of this section and its aspirational goal did *not* meaningfully change. In the 2009 Stategic Plan and almost all subsequent updates, the aspirational goal for research related to this question was, "Causes of ASD will be discovered that inform prognosis and treatments and lead to prevention/preemption of the challenges and disabilities of ASD" (IACC 2009a:16). In the 2016-2017 update, the goal was slightly modified to read, "Causes of ASD will be discovered that inform diagnosis, prognosis, and interventions and lead to prevention or preemption of the challenges and disabilities of ASD" (IACC 2017b:29). Thus the change in the question's phrasing, and the crediting of the neurodiversity movement, represented a cosmetic change meant to appease self-advocates' concerns while maintaining a disease framing of autism, leaving it squarely within the medical model and thus within the realm of State biopower to address.

CHAPTER VI

CONCLUSION

In the above discussion, I have traced the process by which the IACC changed the language of prevention in its Strategic Plan documents between 2009 and 2017. The shift in the focus of "prevention" from the prevention of autism itself to the prevention of its most disabling aspects was gradual and often contentious, as can be seen in the frequent oscillations between statements that what prevention "really means" is improving quality of life, and the underlying drive to show success in "bending the curve" (IACC 2014b:208) of the autism epidemic by reducing diagnoses. Much of this tension represented an attempt to find a compromise between competing biological citizenship claims based on two very different ways of framing autism.

One of these claims came primarily from individuals and organizations representing parents and other family members of autistic people, what Orsini (2009) called the "autism advocacy" movement. Autism here was framed as a growing public health problem that the government needed to address, and by and large, the government's framing of autism coincided with this viewpoint. The other claim came primarily from autistic self-advocates, who framed autism as a condition that, while frequently challenging, also includes strengths that would be lost if autism were eliminated. In addition, self-advocates often presented autism as something intrinsic to autistic people, making its prevention equivalent to preventing autistic people from existing, something that self-advocates explicitly connected to eugenics.

In response to these conflicting frames and their resulting biological citizenship claims, the IACC leadership, representing the State, attempted to appease both sides of

the issue by changing the language in its Strategic Plan to make the focus of prevention not "autism" per se, but autism's "disabling aspects." Doing so allowed it to incorporate some aspects of self-advocates' framing of autism to avoid the appearance of endorsing eugenics, while at the same time maintaining a primarily medical-model approach to the prevention of disability. Thus, this case represents another example of subsumptive orthodoxy (Decouteau & Daniel 2020) in the biopolitics of autism, and highlights both the importance of framing in understanding biological citizenship claims and the persistence of the biopower State in asserting the need to regulate the existence of disability in the population.

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