

# Making sense of autism: Progressive engagement with science among parents of young, recently diagnosed autistic children

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## Abstract

This exploratory study examines the significance of science to parents whose children were recently diagnosed with an autism spectrum disorder. It asks: (1) In what manner did science emerge in parents' concerns and resources as they attempted to understand and advocate for their children? (2) Did some parents engage with science in a qualitatively deeper or more intense manner? Using longitudinal data from interviews and a novel data collection strategy called engagement mapping, it shows that parents asked questions and used resources that were strongly associated with science, but these were vastly outnumbered by "near-science" concerns and resources that mingled meanings from science and daily life. Several parents in the study wove together concerns and resources in an iterative pattern referred to here as progressive engagement with science.

## Keywords

engagement mapping, lay expertise, public engagement, public understanding of science, scientific literacy, sociology of health and illness

## 1. Introduction

How and why does science matter in everyday life? Twenty years of research in this journal and others like it have provided few compelling answers to this question. Deficit-oriented researchers reveal what people know about science, but less about how knowledge affects their wellbeing (Layton et al., 1993). Media researchers unpack the portrayal of science in the news and online, but rarely explore how people use media in social context (Laslo, Baram-Tsabari and Lewenstein, 2011). Even ethnographic researchers, who get closest to the interface between science and local culture, typically emphasize movements and communities, focusing little on why people join a movement, or how community membership helps them address their concerns (Epstein, 2008).

This study starts with the richness of individual experience. In it, I examine the significance of science but I do not assume that science is helpful, nor do I set targets for public understanding or

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engagement. Instead, I build on the work of sociologists who study competence and empowerment in groups frequently portrayed as passive or irrational. These researchers examine how local expertise matters in encounters with science (e.g., Wynne, 1992), how people set purposeful boundaries on their needs for knowledge (Michael, 1996), and how social action can incorporate science without being defined by it (Brown et al., 2006).

Much of this research bears the label “engagement with science.” The word engagement is used differently in psychology (e.g., Maslach, Schaufeli and Leiter, 2001), political science (e.g., Carpini, Cook and Jacobs, 2004), and sociology (e.g., Irwin and Michael, 2003). In all disciplines, however, engagement is about connections, whether they are the *intra*-personal, conceptual and emotional connections that transform previously uninteresting topics into matters of personal concern, or the *inter*-personal, social connections that support action. In this study, I define engagement with science in a broad, interdisciplinary way as *the intra- and inter-personal process of connecting science with lived experience*. This definition clearly establishes engagement as something people do (i.e., the public engaging with science) rather than something that is done to them (i.e., mechanisms for engaging the public).

### *Autism spectrum disorders*

This study explores the role of science in people’s thoughts and actions as they face a deeply personal challenge—a child’s diagnosis with an autism spectrum disorder<sup>1</sup> (ASD). Research on ASDs exemplifies science in the making (Latour, 1987). Credentialed experts disagree on fundamental matters, such as whether or not “autism” is a meaningful diagnostic category (e.g., Snow and Lecavalier, 2011). ASDs are also controversial, with ongoing debates about diagnosis, etiology, and treatment (Silverman, 2011). Because ASDs affect more than one in 100 children in the USA and other industrialized nations (King and Bearman, 2009), scientific credibility is contested in an unusually public manner (Gieryn, 1999), and scientific controversies have a profound impact on millions of families who must choose what to believe, whom to trust, and what to do next (Epstein, 1998).

This study does not offer a macroscopic picture of public knowledge and attitudes (e.g., Casiday et al., 2006), nor does it examine a particular controversy (e.g., Clarke, 2010). Instead, it explores the intimate territory of family life. Gray describes how ongoing scientific uncertainty affects the daily lives of parents, noting how

the weakness of the biomedical model, coupled with the extremely disabling nature of the disorder, presents severe difficulties for parents in terms of parenting and in dealing with their own and their other children’s emotional well-being. (Gray, 1995: 99)

Although ASD research is evolving rapidly, uncertainty and controversy continue to challenge affected families (Silverman, 2011). Like Gray, many researchers focus on how families “cope” with ASDs (e.g., Abbeduto et al., 2004). The coping perspective is grounded in family experiences but often ignores the creative and pro-active aspects of parenting work and says little about the usefulness of scientific knowledge. By following a small set of parents over time, I sought to understand how, when, and for whom engagement with science mattered.

### *What is science?*

Identifying science in daily life is a difficult task. Science is a category that changes across contexts and over time; even in the absence of controversy, no methodological principle reliably distinguishes science from non-science (Gieryn, 1999). In this study, I used two decision

rules to identify science. First, I accepted participants' references to "science" at face value—a necessity, given that participants rarely possessed or provided enough detail to facilitate fine epistemic distinctions. Second, I classified questions, explanations, people, and institutions based on their association with what might be called "officially sanctioned science": research funded by or undertaken within institutions (e.g., research universities, the National Institutes of Health) whose claim to the label "science" is not (currently) a matter of broad public controversy. This definition solves some problems and creates others. It undeniably privileges mainstream and socially normative science at the expense of fringe and contested science. More salient to this paper, it produces an area of ambiguity that I called "near-science." I discuss near-science below, but because it is likely to be controversial I wish to clarify here that the "near" in near-science is a matter of association, not similarity. Near-science resources are people who have social access to knowledge about research, even if they don't have that knowledge first-hand. They are not people who do something science-like, or have partial scientific training. Near-science questions are questions that provoke or imply questions about science; they are not "almost scientific questions."

### *Goals and research questions*

My primary goal in this study was to develop theoretical and methodological tools for examining the role and significance of science in everyday life: science that "relates in reflexive ways to the concerns, interests and activities of citizens as they go about their everyday business" (Jenkins, 1999: 704). I also sought to collect data rich enough to support analysis using constructs from the qualitative sociology of science—theoretical tools such as Galison's "trading zones" or Star and Griesemer's "boundary objects" that address the exchange and transformation of knowledge. My methods were not designed to produce generalizable conclusions about a group of people, but rather to facilitate exploration of new research strategies and new ideas. To this end, I posed two research questions: (1) In what manner does science emerge in parents' concerns and resources as they attempt to understand and advocate for their children? (2) Do some parents engage with science in a qualitatively deeper or more intense manner, and if so, why?

## **2. Design and methods**

### *Recruitment*

Parents of young, recently diagnosed children were recruited through an ASD clinic associated with a large health management organization in California. Recruitment was limited to four counties encompassing considerable ethnic and socio-economic diversity. A letter containing a stamped response card was sent to every family in the clinic database with at least one ASD-diagnosed child between 18 months and 6 years of age<sup>2</sup> who had received the diagnosis 6–24 months<sup>3</sup> prior to mailing. The response rate, though low (22 of 146, or ~15%), was not surprising given the intrusive nature of the study, the absence of incentives, and the logistical challenges facing parents of children with special needs (cf. Heinrichs et al., 2005). Sixteen of the 22 respondents agreed to an in-person meeting; fifteen gave informed consent. To insure that parents understood the demands of participation, I asked participants to re-consent after two interviews. Only one declined. Two other participants did not complete<sup>4</sup> the first two interviews, and one participant moved away before the end of the study. Owing to the demands of data collection, only ten of the eleven parents who agreed to continue were included in the final sample. All ten completed the study.

### Sample characteristics

The final sample was diverse with respect to educational attainment and locally available resources but had no representation from the local African-American and Latino populations (see Table 1). Parents in the sample were somewhat more educated than the general population. Women (80%) were over-represented, presumably because I interviewed the primary childcare provider from each family. In terms of diagnosis, the children of parents in the sample were not statistically different from the population of children diagnosed by the collaborating clinic, though formal diagnoses may obscure some subtle differences. Parents in the sample were almost evenly divided among high, medium and low-resource school districts (a qualitative categorization based on conversations with parents and clinicians about the services available to children with special needs).

### Data collection and analysis

Interviews were conducted over a nine-month period during 2006–7. I chose a longitudinal design because I expected engagement with science to be rare, dynamic, and context-specific. This design raised the chance of seeing engagement within each case and also enabled me to understand its significance relative to other life events. I followed all participants for a minimum of six months, during which time each completed at least six in-person, semi-structured interviews lasting 45–60 minutes. Time between in-person interviews varied from four to seven weeks depending on ease of scheduling. During the second half of the study, I added shorter (10–15 minute) telephone interviews between in-person interviews. These were intended to increase the validity of the data by identifying high-salience topics for follow-up during in-person interviews. Participation concluded

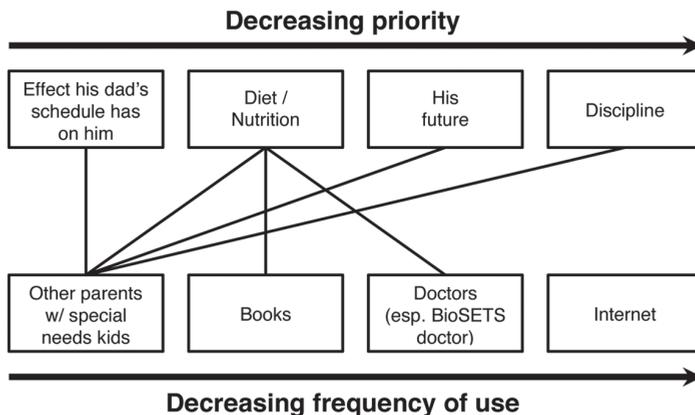
**Table 1.** Final participant sample. The diagnosis listed here is the first given by the collaborating clinic—not necessarily the child's final diagnosis, or the one that the parents used to describe him/her.

Parent's pseudonym	Child's pseudonym	Child's age at first interview	Child's formal diagnosis	Parent's education attainment	Parent's race	School district resource level
Alice	Robin	3y 11m	Autistic disorder	BS—Mathematics	Asian	High
Anna Mary	Jason Noel	2y 5m 2y 11m	PDD-NOS Autistic disorder	BS—Business High school diploma	Caucasian Caucasian	Medium Low
Reed	Colin	3y 11m	Autistic disorder	BA—unknown; some law school	Caucasian	High
Sara Sharon	Harriet Travis	4y 11m 2y 2m	PDD-NOS Autistic disorder	High school diploma Some college	Caucasian Caucasian	Medium Low
Sherri	Alex	3y 10m	Autistic disorder	BA—English Literature	Caucasian	High
Suzanne	Matthew	5y 9m	Autistic disorder	BA—Education; elementary teaching credential	Asian	Low
Tammi Walter	Jeremy Timothy	7y 6m 4y 9m	PDD-NOS Autistic disorder	High school diploma MS—Electrical Engineering	Caucasian Asian	Medium High

with the sixth in-person interview *or* the first interview conducted after six months, whichever came later.<sup>5</sup> Participants completed an average of ten interviews including tracking interviews (min = 8, max = 12, mode = 9).

Interviews focused on participants' concerns about their children's conditions and the resources that they used or planned to use to address those concerns. This follows from the definition of engagement with science stated in the introduction: a participant's concerns were presumed to reveal something about the intra-personal side of engagement with science, while her resources were presumed to reveal something about the inter-personal side. All interviews began with open-ended questions about the participant's wellbeing, recent events in the child's life, the participant's concerns about the affected child, and resources that the participant had used to address these concerns (including people and organizations as well as media resources). During in-person interviews, these questions were followed by generic and participant-specific probes for additional information (e.g., "anything else?", "how was your conversation with the psychiatrist?"). All in-person interviews were recorded and professionally transcribed. Telephone interviews were transcribed when necessary to supply a quote or resolve an ambiguity in the in-person interviews.

All in-person interviews concluded with a novel data collection technique called engagement mapping. Engagement mapping produces a representation of recent thoughts and actions related to a particular topic, and is intended to reveal how participants perceive their own activity (see Figure 1). First, I invited a participant to list her "big picture" questions and concerns on separate Post-it notes. This task was framed broadly ("autism or your child's condition") to encompass issues that were clearly ASD-related as well as broader issues that the participant found relevant. I then asked the participant to line up her concerns in order from "most important" to "least important" on the top of a large piece of paper. When this was completed, I asked the participant to list the resources she used or planned to use to address her concerns. Participants were allowed to lump people together into categories ("doctors") or list particular individuals based on the assumption that participants would use a level of specificity that made sense to them. When the participant finished listing resources, I asked her to arrange them in order from most frequently used to least frequently used along the bottom of the same sheet of paper.



**Figure 1.** The engagement map from Sherri's fifth interview. Concerns are listed across the top, resources across the bottom.

Finally, I asked the participant to draw lines connecting each concern with the resources that she used or planned to use to address it, encouraging her to connect more than one resource to each concern if relevant. Throughout the process, if prominent concerns or resources from earlier in the interview were not mentioned, I asked the participant if she would like to include them. This increased consistency between the question-and-answer and engagement mapping portions of the interview. Engagement mapping enabled participants to place their interests and actions in an overall context and revealed much about the subjective importance of particular topics. It also increased the thoroughness of each interview by surfacing topics that had not arisen naturally. Finally, engagement mapping offered an efficient way to examine changes in participants' engagement over time.

### 3. Results

This section is divided into two subsections corresponding to my two research questions. In the first subsection, I use data from engagement maps to examine the emergence of science in parents' concerns and resources. In the second subsection, I draw on interview data to examine unusually intense engagement with science. For this within-case and comparative analysis, I used a version of grounded theory (Strauss and Corbin, 2008) in which theoretical premises were derived from and tested against data in an iterative process of theory articulation, data consultation and theory revision. This was supported by interview summaries generated within 24 hours of each interview, thematic memos developed during data collection, and participant narratives developed from interview summaries and transcripts.

#### *In what manner does science emerge in the concerns and resources of parents as they attempt to understand and advocate for their children?*

During engagement mapping, I encouraged participants to speak broadly about their concerns and resources without restricting the discussion to science. This produced complex accounts in which the place of science was not always clear. During analysis, I first identified the concerns and resources that were unambiguously associated with "officially sanctioned science" (as discussed above). In the case of parents' resources, these were people directly involved in ASD research, or whose professional specialization required familiarity with the primary research literature on ASDs. In the case of parents' concerns, these were either explicit references to science or questions whose language and content matched the formal language and content of scientific research (as represented by published articles, requests for proposals, etc.). Very few of parents' resources and concerns fell into this narrowly defined *science* category. More significantly, many of the remaining concerns and resources implied a possible connection with science. To capture this more ambiguous aspect of engagement with science, I divided the remaining concerns and resources into two groups: *near-science* and *non-science*.

The distinction between near-science and non-science is analytically important and worth discussing at length. As a rule of thumb, near-science resources and concerns can be thought of as one degree away from science. This means something slightly different for resources than it does for concerns. For parents' resources, *near-science* indicates social proximity to people who know about relevant research. Near-science resources may not know a great deal about ASD research, but they probably have access to someone who does. Primary care physicians fall into this category, as do non-physician professionals like occupational therapists and special education teachers, as well as dedicated parent activists. This classification system

emphasizes the value of tacit knowledge: someone with less scientific training but more social access might be less prepared to interpret the results of a research study but *more* prepared to understand the practical implications of that study, the relationship of findings to other similar findings, and unpublished “scuttlebutt” (rumor) about the quality of the research. Such topic-specific knowledge can be powerful in the right contexts: with respect to ASDs, a behavioral therapist can be considered a more scientific resource than a PhD-level researcher in particle physics.

If near-science resources are one person away from ASD research, near-science concerns are one *question* away from ASD research. Socially and epistemologically complex, near-science concerns have many questions imbedded in them—questions of priority, cost, and morality, as well as questions that “officially sanctioned science” attempts to answer.<sup>6</sup> In this study, near-science questions were often focused on a particular child’s unique circumstances, rather than more general how and why concerns. To understand what this means, compare the question “what genetic factors contribute to autism?” with the question “will my child ever have autistic children?” The first question mirrors questions asked by scientists and granting agencies, thereby fitting the narrow definition of science concerns used above. The second question does not, but it may lead to the first question, along with many other questions that are not within the territory of science (e.g., “will my child ever get married and have children?”).

This is only one of many possible strategies for sorting parents’ questions and resources. It has distinct flaws, including the need to infer which people have social access to research and which questions are likely to lead to science questions. Furthermore, because the science/near-science/non-science classification system focuses on *social* proximity to research, it was difficult to apply to media resources. This problem was exacerbated by participants’ tendency to refer to their media resources by category (e.g., “parent books,” “the Internet,” or “autism websites”), offering insufficient information for me to classify them accurately. To avoid the false appearance of precision, I lumped all media resources (27% of the resources listed) into an undifferentiated category called “media.” The lack of resolution with regard to these important resources is a shortcoming of the interview and analysis protocols that will be addressed in future research. Still, this study’s focus on inter-personal resources should provide a useful complement to the ample attention that media resources have received elsewhere.

Ultimately, the important question is not “is this system perfect?” but “is it good enough to reveal something new about the relevance of science?” It is difficult to imagine any system that could classify parents’ idiosyncratic concerns and resources without ambiguity or inference. I propose *near-science* as one possible way of dealing with concerns and resources that are near the social world of science without belonging to it—an important grey area in public engagement with science.

Table 2 summarizes the categorization process and results. The distribution of parents’ concerns was consistent across cases. Science concerns were present in every case, but represented less than a sixth of parent concerns on average, and with one exception, never more than a quarter. Near-science concerns were more common, representing over a third of parent questions on average, and, with one exception, never *less* than a quarter. At first glance, the distribution of parents’ resources was similar, with a small fraction of science resources and a much larger fraction of near-science resources. There was, however, one important difference. Whereas every parent posed at least one concern in the science category, three parents never used a resource in the science category. These three parents were not otherwise similar—one used more near-science resources than any other parent (78%), while another used fewer near-science resources than any other parent (17.6%).

**Table 2.** Categorization of concerns and resources. The resource categorization omits media resources, which represented median 24.3, mean 27.9, SD 11.6 of resources parents listed in their engagement maps.

	Parents' concerns			Parents' resources		
	Category definition	Examples	% of questions Median Mean (SD)	Category definition	Examples	% of questions Median Mean (SD)
Science	Questions that explicitly mention science, scientists or scientific research; and questions that reiterate scientific research questions	Is there any study that speaks on the different demographics of affected people?  How does speech delay correlate with other symptoms of ASD?	<b>12.7</b> 14.8 (9.3)	People directly involved in autism research; people who have direct familiarity with the primary autism research literature	Psychiatrist specializing in autism diagnosis  Autism geneticist  Psychologist conducting research on pivotal response therapy	<b>7.2</b> 11.2 (15.5)
Near-science	Questions that are likely to lead to science questions	What can I do to help improve their social skills?  What is it that makes him out of control?	<b>37.5</b> 40.5 (16.7)	People with social access to science resources; likely to read the secondary ("grey") autism research literature	Pediatrician  Behavioral therapist  Editor of ASD research newsletter	<b>40.0</b> 41.6 (17.9)
Non-science	Questions about local services, ethics, immediate practical concerns or the unknowable future	Are there any programs for siblings of kids with autism nearby?	<b>49.1</b> 44.7 (17.2)	People with no more knowledge of autism research than the average citizen	School principal  Parents with non-ASD children	<b>21.9</b> 20.5 (14.0)

There is some evidence that parents coordinated the "science-ness" of their concerns and resources (see Figure 2). Parents were more likely to connect a science resource to a science concern than a near-science or non-science concern. Conversely, parents were more likely to connect a non-science resource to a non-science concern than a science or near-science concern. These

findings support the validity of the science/near-science/non-science coding categories, which seem to match how parents saw their questions and resources. They also suggest that parents were discerning in the type of resources they sought for particular concerns.

Two other interesting findings emerge from the data in Figure 2. First, near-science resources were more popular than science or non-science resources with every type of concern. This suggests that parents perceived people who were not researchers but had some access to specialized knowledge to be more available or useful regardless of the question. Second, parents saw media resources as more relevant to their science questions than their near- or non-science questions, and consulted media resources about their science questions more frequently than any other type of resource. Not surprisingly, “the Internet” was the most commonly listed media resource; it was also the media resource that parents connected most consistently with their science questions. This finding agrees with survey-based evidence that the Internet is the most popular resource for those seeking answers to specific science-related questions (National Science Board, 2008). As Figure 2 also shows, though, the Internet is far from the only resource that parents connected with their science questions.

### *Do some parents engage with science in a qualitatively deeper or more intense manner?*

Some concerns and resources matter more than others, and the practical significance of engagement with science may only be visible in the evolution of concerns and resources over time. This section exploits the study’s longitudinal design to examine the connection between questions and resources. It focuses on an iterative pattern called *progressive engagement with science* that shows how science-related questions and resources can be woven together in personally significant ways.

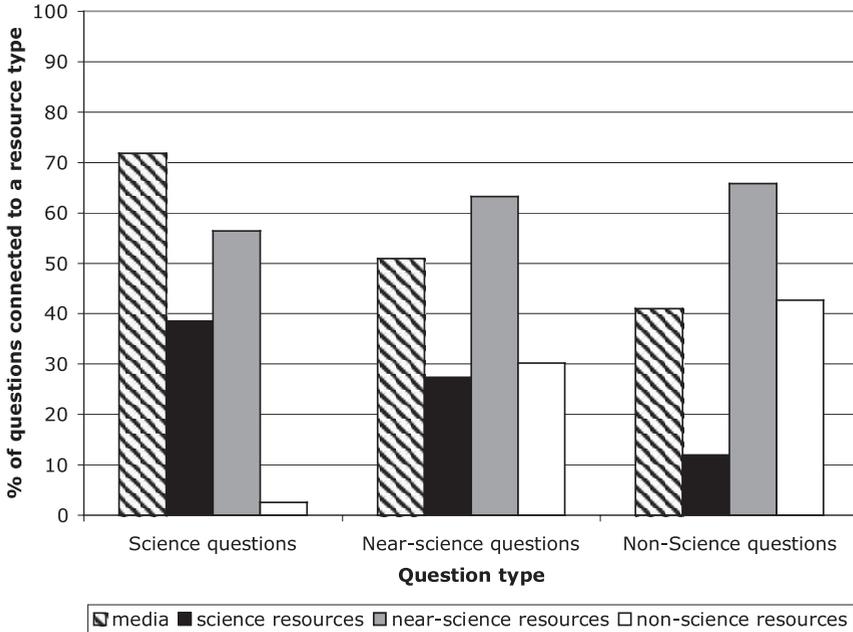
Sara’s five-year-old daughter was diagnosed with PDD-NOS. Four interviews into the study, Sara became concerned that her daughter also had dyslexia. In Sara’s words:

... she’s been practicing writing her name for a couple months now, you know, to the point where she’s perfecting her letters. All of a sudden, she flipped it so she’s writing her name H, no, it was t-e-i-r-r-a-H. [WOW!] The letters were represented perfectly ... I’m thinking, okay, she’s a sorter, she’s a liner-upper, maybe it’s just, and then, you know, I got to worry about dyslexia and my imagination went [WENT A LITTLE CRAZY?] Right off the deep end, and I started to, like, “Oh, my God, what am I going to do?!”

Rather than calling her doctor or looking for a book on dyslexia, Sara investigated a series of more specific questions. First, she

... got back into my little group of friends and stuff and talked with the other mommies, you know, “Is this normal?” Because my first child, he would flip his R’s, which is pretty typical, you know, and an N here and there, but never the *whole* word. And, you know. So, I’m like, okay, what is dyslexia? What should I be looking for? Should I be worried about it? So, talking to friends, and they’re going, “Well, that’s kind of weird.” ... next step I check online for, you know, testing of dyslexia and I guess it doesn’t happen ’til, like, they’re seven. [RIGHT.] So, I’m like, “Okay, great. Now what?” So, I called Dr. S and she’s fine, it’s okay. It’s okay. It’s probably just the way she’s learning her spelling. And I’m like, “All right. All right. I feel a little better now.”

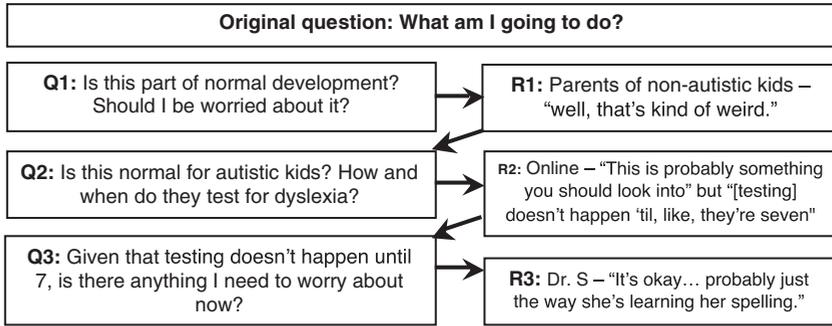
Later in the interview, Sara discussed each step of this process, revealing the underlying strategy. Sara often spoke to friends with “normal kids” when she was “trying to clear the line



**Figure 2.** The match between parents’ concerns and resources. Columns refer to the percentage of concerns in a particular category that parents connected with resources in a particular category. Parents could connect each concern to more than one resource, so the percentages do not add up to 100.

between typical and not typical.” In this case, her friends validated her concern. She then moved on to her next step: using search engines and health information websites to seek out information about dyslexia. This process was intended to help her “decide if that was something I needed to take to a doctor or if it was something that I should just, you know, work on at home.” Her findings were ambiguous: dyslexia websites indicated that dyslexia didn’t typically emerge at that age and in that way, but parents in the online autism support groups described similar phenomena and shared similar worries. Only then, armed with information about normal development, dyslexia, and the co-morbidity of dyslexia and autism, did she seek out an autism specialist to resolve the remaining ambiguity. By then, her initial question, “What am I going to do?” had transformed into “Is this something I should worry about right now?” The doctor reassured Sara that no, dyslexia was not something she should worry about for the time being.

Sara’s evolving concern about dyslexia offers an unusually clear illustration of engagement with science, as defined in this paper: the inter-personal and intra-personal process of connecting science with lived experience. Her story can be interpreted as a single, evolving line of inquiry or as an iterative series of interactions, each of which changed Sara’s understanding of the problem she faced. Although her concerns were not necessarily becoming more scientific, the progress Sara made with respect to her own questions led me to call this pattern *progressive engagement with science*: engagement that develops over time through iterative interaction between concerns and resources. Figure 3 shows a schematic representation of Sara’s account.



**Figure 3.** A schematic representation of Sara's progressive engagement with science. Boxes marked Q refer to questions Sara asked during interviews, while boxes marked R refer to resources that Sara reported using.

A second, more elaborate example of progressive engagement with science comes from the case of Sherri, whose four-year-old son Alex was diagnosed with Asperger's Syndrome. For most of the study, Sherri was worried about Alex's aggression toward his two-year-old sister. Her concern evolved over four months, leading up to a crisis in the seventh interview. At first, she situated her concern ("how do I stop the hitting?") within the broader category of behaviors that worried her. Later, like Sara, she split her initial concern into several more specific, related questions:

... is he ever going to grow out of that? And why does he only do that to her? And why does he wait until we're not looking? He knows it's wrong so he knows, you know, he shouldn't do it, so what's, you know, what's going on there?

These questions reflect a shift away from immediate action ("what do I do?") and toward a deeper concern for explanation and prediction. After books left her unsatisfied ("there wasn't anything really [along the lines of] here's how you teach a kid with autism empathy"), Sherri consulted with a friend, also the mother of an autistic child, who suggested that Alex was resorting to aggression because communication problems related to his disorder left him without other ways to express frustration or jealousy.

Sherri spent the next six weeks "trying to think of a way to help him understand that it's not ok, and to help him express what he needs to express." Her improvised strategies led to a brief lull in worrisome incidents before Alex's aggressive behavior began to worsen, spreading from home to school and day care settings. In this context, Sherri framed a number of different, very specific concerns. She wanted to know whether aggressive behavior was normal for children with ASDs or whether Alex might have a second, unrelated condition. She also began to question whether particular aspects of Alex's treatment regime, a mix of mainstream behavioral therapies, alternative dietary regimes, and vitamin supplementation, might be exacerbating his behavior. Finally, she developed a theory that Alex was responding to fluctuations in the work schedule of his father, an airline pilot:

Alex is so routine, you know, I've wondered a lot of times is his behavior ... just a venting of frustration about the inconsistency in his schedule? ... I'm trying to find out how can I narrow it down ...

Sherri made appointments with a psychologist and a behavioral therapist, and returned to the bookstore. She also began keeping careful notes on the timing of Alex's outbursts. This combination of approaches paid off. A book written by autism specialists reinforced her friend's explanation and convinced her that communication problems, normal for Asperger's Syndrome, could contribute to Alex's behavior. The behavioral therapist elaborated on the practical tips in the book, giving Sherri concrete strategies for responding to Alex's violent outbursts. Finally, Sherri's own careful observations taught her that Alex's aggression was associated with both his father's schedule and injections of vitamin B-12, a treatment she adopted on the advice of an alternative health<sup>8</sup> practitioner. Six months after she first broached the subject, Sherri finally felt that she knew enough to respond effectively.

There are certain obvious similarities between Sherri's case and Sara's case. Both started with a practical "what do I do?" question tied to a disturbing behavior pattern. This initial question led to a broader "why?" question that split into multiple lines of inquiry, some of which connected the parent's immediate concern to scientific research related to autism. Earlier concerns and resources set the stage for later ones. Thus, before speaking with her doctor, Sara had already learned from the Internet that dyslexia isn't usually diagnosed until the age of seven. Before reading about communication and aggression in a specialist-authored book, Sherri had already discussed this possibility with a friend. Whether we interpret this as redundancy or as triangulation, it is clear that Sherri and Sara drew on a range of resources, integrating information from friends, professionals, and media sources. For both, it seemed to be the combination of resources that helped them reach a stopping point. Within each case, the iterative pattern of progressive engagement was confined to a particular theme. While Sara and Sherri pursued these themes in a distinctly dynamic manner, they also posed more static concerns, raised concerns that they later abandoned, or found simple answers that did not provoke new questions. For both of them, progressive engagement was a thread running through their activity, a series of connected episodes that stood out among other, more isolated and less dynamic interactions.

Notably, neither example would qualify as engagement with science under a narrowly restrictive definition of *science*. Although both parents raised science concerns that fit the narrow definition above (e.g., "how many autistic kids ... are known to have some sort of dyslexia?"), those questions were outnumbered by near-science questions (e.g., "how do I get him to stop hitting his sister?"). Both parents used several near-science resources (e.g., Sherri's behavior specialist) but only Sara used a narrowly defined science resource (Dr. S, who is a specialist in an autism-related field). One must pay attention to near-science resources to see these as examples of progressive engagement with *science*.

Even under this more expansive definition, progressive engagement with science was relatively rare. It was far more common for parents to pose science and near-science concerns in isolated incidents, to repeat those concerns periodically without apparent progress, or to pose such concerns but never seek out science or near-science resources to address them. Only half of the parents in the sample connected science and near-science concerns with science and near-science resources in the evolving, iterative pattern described above. More strikingly, only one case contained multiple clear instances of progressive engagement with science. Some parents followed progressive lines of inquiry that did not involve science. For example, more than one parent became deeply involved in the administrative logistics of a child's school placement. The rarity of progressive engagement with science provokes a new question: Why do some parents do it while others do not?

## 4. Discussion

### *Exploring the determinants of progressive engagement with science*

This exploratory study cannot provide conclusive evidence about the circumstances that lead to progressive engagement with science. It can, however, cast doubt on a few intuitive hypotheses and suggest an alternative. Within this sample, progressive engagement with science was *not* associated with educational attainment, convenient access to ASD resources, or severe symptoms. Furthermore, although I did not use a formal measure of attitudes, parents who progressively engaged with science did not seem to express more positive attitudes toward science. Sherri, for example, was deeply skeptical about mainstream medical science for much of the study, while Walter, who did not progressively engage with science, repeatedly asserted his preference for scientific facts over personal stories.

What *did* seem to predict progressive engagement with science was a parent's interest in the idea of "autism" and her willingness to explore autism as a way of explaining her child's symptoms. All parents in the study struggled with the diagnostic labels their children received. Only five parents—the ones who progressively engaged with science—consistently thought about the nature of autism or returned, repeatedly, to the idea of autism as a way of explaining their children's behavior. Of the remaining five parents—those who did not progressively engage with science—three found individual symptoms more useful than the over-arching label. In Tammi's words, an autism diagnosis "doesn't really tell you anything about a child"; instead, "you have to break it down into smaller areas ... I'd rather focus on my individual kids and their individual problems." These parents were also inclined to minimize their children's diagnoses, referring to them as "a little bit autistic" (Walter) or describing their characteristic symptoms as "acting silly" (Suzanne). The other two parents, Anna and Mary, focused on understanding the systems of care that serve children with special needs. They readily identified their children as autistic, but, like Walter, Tammi, and Suzanne, they found limited value in scientific explanations. Rather than exploring the nature of autism, their questions focused on the local availability of services and how to get those services to work for their children. For them, autism was a sort of diagnostic currency they could use to access better services.

### *Summary and limitations*

The results of this study show that science, even narrowly defined, mattered to some degree for all parents in the sample: all raised science concerns and most used science resources at some point over the course of six months. Furthermore, parents tended to choose science resources to help them with science concerns and non-science resources to help them with non-science concerns. Science concerns and science resources arose far less often, however, than concerns and resources in the ambiguous territory of near-science. Finally, and intriguingly, half of the parents in the study engaged with science in a qualitatively deeper and more intense way that I call progressive engagement with science. These parents did not differ from others in educational attainment or access to ASD services, and they expressed similarly varied attitudes toward science. The only thing that seemed to set them apart was a greater interest in "autism" as a way of understanding their children.

These results should be read with three limitations in mind. First, although the participants were educationally and economically diverse, they did not reflect the full diversity of the population—a population that is itself situated within a particular geographic, institutional, and historical context.

Furthermore, parents who agree to participate in a research study might have more positive attitudes toward science, and more interest in research, than other parents of autistic children. Although the data did not suggest a strong connection between attitudes toward science and progressive engagement, this recruitment bias might still make progressive engagement with science more likely in this sample. For these reasons, we cannot assume that the patterns revealed in this study are typical of all parents with autistic children, much less all people with other science-inflected concerns. Second, because of the intensity of data collection, this study is vulnerable to research effects—the possibility that participation altered the behavior of participants. This limitation increases the uncertainty surrounding the overall trends described in the first part of the results section. It is less relevant to the findings on progressive engagement, which rely on differences among cases within the sample.

Finally, there is an unavoidable element of subjectivity in the classification of concerns and resources, as well as the identification of progressive engagement with science. This is mitigated by the use of analytic strategies intended to increase the validity of qualitative analysis, including triangulation among multiple interviews and instruments. Because of the highly situated nature of the data, however, it was not practicable to use other strategies, such as inter-rater reliability tests (Barbour, 2001). A second coder would have needed to be familiar with both the subject matter context (ASD treatment and research) and the full body<sup>9</sup> of data. In light of these limitations, the value of this study lies not in its ability to support general claims, but rather in its capacity to reveal patterns that might be found elsewhere and to generate theories about the significance of those patterns.

### *Theoretical implications of this research*

At one level, this study simply offers a new perspective on the role of science in the lives of non-scientists, demonstrating how science percolates through the concerns and actions of parents with autistic children. It also draws attention to the useful borderland of near-science—a middle ground occupied by people with indirect access to research, and by concerns that provoke an interest in science. The near-science category is part of a long history of scholarly efforts to label things that seem close to, but not the same as, scientific work (e.g., Weinberg, 1972). Hopefully it prefaces other, more sophisticated analytic tools. If the results of this study are any indication, however, near-science concerns and resources are an important key to understanding engagement with science.

It is interesting to consider why the idea of “autism” appeared to influence parents’ engagement with science. Borrowing a familiar construct from the sociology of science, autism might be thought of as a boundary object between the world of parents and the worlds of medical science. According to Star and Griesemer, boundary objects

have different meanings in different social worlds but their structure is common enough to more than one world to make them recognizable, a means of translation. The creation and management of boundary objects is a key process in developing and maintaining coherence across intersecting social worlds. (1989: 393)

The discussion of boundaries between social and epistemic worlds also evokes Galison’s (1997) idea of trading zones. Galison, in his study of particle physicists, drew inspiration from anthropological research that showed how different cultures interact

most notably by trade. Two groups can agree on rules of exchange even if they ascribe utterly different significance to the objects being exchanged; they may even disagree on the meaning of the exchange

process itself. Nonetheless, the trading partners can hammer out a local coordination despite vast global differences. (1997: 783)

The idea of trading zones offers a rich and under-exploited framework for analyzing public engagement with science. Scholars have applied Galison's framework to numerous cases of communication and collaboration between fields of expertise (e.g., Gorman, 2010), but few have applied it to the communication, collaboration, and conflict between scientists and laypeople. It is easy to re-imagine progressive engagement with science as a purposeful journey back and forth between social worlds. In this light, autism is the focus of trade, the common interest around which parents and doctors forge "an effective, though limited, coordination between beliefs and actions" (Galison, 1997: 813).

Even on its own, the idea of progressive engagement has considerable potential for the field of public engagement with science, which currently offers few tools for connecting what individuals know, think, and feel with their highly contextualized social interactions and their participation in communities and networks. Progressive engagement with science is one way of conceptualizing how people weave multiple sources together in purpose-driven and dynamic inquiry that connects science with daily life. It makes an explicit connection between the inter-personal and intra-personal dimensions of engagement (i.e., resources and concerns). It also describes the *sort* of engagement that might lead to participation in organized communities and social movements. Finding and tracking progressive engagement is challenging, but the engagement mapping technique introduced in this study holds some promise as a tool for capturing engagement efficiently, albeit at a lower level of resolution. In future research, I will examine whether or not this tool offers sufficient detail and validity when used alone.

### *Practical implications of this study*

What good is progressive engagement with science for those who do it? The parents who participated in this study undertook many projects, achieved goals of personal value, and acquired insights that are impressive from any vantage point. Regarding the *purposes* of their work though, little should be taken for granted. What they did, from their perspective, was almost always about their families. At times it was about autism, but it was just as often about parenthood, society, and normalcy. The prevalence of near-science questions and resources shows that science is part of their thoughts and actions. It also confirms that science, as such, is rarely in the foreground. We should neither underestimate nor overestimate what science can do for them.

With that caution in mind, progressive engagement with science appeared to be helpful in three ways. First, as illustrated in Sherri's case, a new explanation, even an imperfect one, often provides some emotional relief. Second, personal connections forged around the idea of autism and the exploration of science may reduce the isolation that so many parents feel (Gray, 1998). There are other ways to establish common cause, but science provides one avenue through which parents can connect with people who share their concerns. Finally, parents who prefer not to think of their children as autistic (a critical precursor to progressive engagement in this study) may have difficulty benchmarking the services that their children receive. Most of the parents in the study worried about whether their children were making adequate progress with the services they received, but Tammi, Suzanne, and Walter—who did not progressively engage with science—expressed anxiety about not even knowing what sort of services to expect.

Not everyone will undertake progressive engagement with science. Irwin and Michael, responding to enthusiastic proponents of scientific citizenship, remarked that "not all citizens will be drawn

to an intensive (or over-energetic) form of engagement” (2003: 148). This is both true and reasonable. Progressive engagement with science is not the easiest course of action, and it may not be the quickest or best way to obtain services for an autistic child. When it does happen, though, it offers a glimpse of how science can be valuable, useful, and even comforting to people in times of need. As such, it is something to be studied and even, perhaps, celebrated.

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## Notes

1. A family of disorders including autism, Asperger’s Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).
2. Technical problems in the clinic’s database led to the inclusion of a small number of parents who fell outside the selection criteria. One parent, whose youngest child received his diagnosis at the age of 6 years 11 months, was included in the final sample.
3. Parents contacted during pilot work reported that the period immediately following diagnosis was one of profound emotional and logistical stresses, placing ethical and practical constraints on research during this period.
4. One parent declined to reschedule the second interview after a scheduling error; the other parent chose to place her autistic child in foster care, and was understandably too distressed to continue.
5. A scheduling error resulted in one participant completing one additional interview beyond this limit.
6. The relationship between science and near-science may remind readers of the concept of *cognitive polyphasia* that Moscovici and his followers use to describe the simultaneous co-existence of different “modalities of knowledge” that we employ purposefully, depending on our social context (Moscovici, [1961] 2008: 191). Owing to space constraints, a more thorough examination of this theoretical resonance and its implications for the idea of progressive engagement with science will have to wait for a future paper.
7. My interjections are bracketed and in capital letters.
8. B-12 injections are known to have a range of side effects, including mood alteration, in some patients.
9. For example, considerable knowledge about autism is required to recognize the scientific relevance of one parent’s concern about head size (not described here), whereas Sherri’s questions about her husband’s work schedule could be misinterpreted without knowledge of previous interviews.

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