

Participation in a Science Festival Promotes Inclusive Science Communication around Autism Spectrum Disorder

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17 **Abstract**

18 As a high prevalence disorder with limited information about etiology, autism spectrum disorder
19 (ASD) has been marked by confusion and miscommunication around its causes and treatments. To
20 promote high-quality science communication, we participated in a local science festival, both
21 providing information about the brain and ASD and asking passersby questions about their
22 knowledge of ASD. We then asked the booth staffers to evaluate the program and conducted
23 qualitative analyses of public and staffer responses. Public responses to the question “what would
24 you like to know about autism?” most often concerned how the disorder was diagnosed or defined.
25 In contrast, public responses to the question “what would you like others to know about autism?”
26 centered around educating those unaffected by ASD on how to improve interactions and
27 awareness, mentioning inclusivity and intersectionality, and dispelling negative stereotypes. The
28 staffers overwhelmingly reported that in future years, they would include even more science and
29 allow for more in-depth conversations with interested parties, as well as bringing materials in other
30 languages. These responses are in keeping with a trend for more inclusive science communication,
31 particularly in the field of behavioral health and ASD, and a desire to challenge myths around the
32 condition. We conclude that our science festival interactions brought multiple benefits to public and
33 staff.

34 **Introduction**

35 Autism spectrum disorder, as defined in the Diagnostic and Statistical Manual of Mental Disorder,
36 Fifth Edition is a neurodevelopmental disorder with key features reflecting impairment in social
37 interactions (e.g., reciprocal communication and social interaction) and difficulties arising from
38 overly circumscribed or repetitive interests, activities and/or behaviors (1). These disorders are
39 present from very early in life, and they range in a spectrum of severity from mild (reflected in
40 persistent difficulties with perspective taking and comprehending affective components of human
41 relations) to very severe (complete withdrawal from social interaction and lack of awareness of
42 socially mediated features of the environment). The recent epidemiological estimate of prevalence
43 from the Centers for Disease Control and Prevention (CDC) are 1 in 54 children overall, with the rate
44 being four times higher in males than in females (2). Age of diagnosis is crucial to receiving early
45 treatment and affecting the trajectory of the condition; given the behavioral nature of ASD,
46 symptoms do change over the lifespan and as a result some percentage of children may move
47 above and below diagnostic thresholds over time (3).

48 In studying the apparent physical underpinnings of ASD, the scientific community has struggled to
49 provide a complete explanation of etiology. Although some estimates point to genetics to account
50 for up to 80% of phenotypic variance (4), the full developmental dynamic for ASD remains to be
51 discerned. This combination of a high prevalence disorder with limited information about etiology
52 creates a dynamic in which misinformation about etiology and treatment of the condition is
53 rampant. While searches for the word “autism” on the internet yield hundreds of millions of hits,
54 the quality of information varies widely and can influence, for example, the opinions of parents on
55 accepting a diagnosis (5) or health policy makers setting standards for coverage of autism treatment
56 (6). Healthcare consumers (as well as providers) often struggle to sort through the overwhelming
57 volume of information to land on an empirically-informed vantage point (6,7). In sum, these are
58 relatively common disorders for which we have limited scientific understanding of etiology, but for

59 which there are effective assessments and empirically supported interventions that offer promising
60 outcomes.

61 Public awareness, understanding, and discussion of ASD has changed substantially in the last 20
62 years, in part due to the sharp rise in number of diagnoses (8) and in part due to the rise in
63 pseudoscience such as rumored links between vaccines and ASD (9). Given the 1 in 58 reported
64 national prevalence for children meeting diagnostic criteria (10), and the increasing depiction of
65 ASD in the media, it is very likely that most people in the US know someone or know of someone
66 with ASD. Self-advocates have played an important role in changing the conversation as well, by
67 describing their experiences and advocating for a shift from “autism awareness” to “autism
68 acceptance,” for example (11). An emerging view in the advocate community is to shift from
69 labeling ASD a “disorder” and instead to view it as part of a spectrum or even a circular rainbow of
70 diverse brain functioning (12,13). This is in keeping with drives for inclusion and recognition of
71 diversity in other communities.

72 Research suggests that these disorders are present across demographic characteristics; however,
73 they are detected at differing rates across gender, race ethnicity, and SES. In the US there are
74 differences in the age of diagnosis and access to care, related to race, ethnicity and socioeconomic
75 status, as well as intersectional concerns (10,14,15). Further, people with developmental disorders
76 like ASD tend to have reduced access to healthcare and health information, as do ethnic and racial
77 minorities and those from lower income households (16). Thus, individuals on the autism spectrum
78 who also come from an underserved demographic group have been particularly poorly served in the
79 healthcare system. Given the emerging evidence base demonstrating the importance of early
80 diagnosis and intervention in ASD (17), there is a clear need for clear and accurate communication
81 around ASD, consistently available to everyone from specialists to the families at their moment of
82 expressing concerns about their child’s development.

83 This additional element in the landscape of ASD research and communication is a dynamic of racial
84 disparity in access to care and related delayed diagnosis and intervention is consistent with the
85 concept of *intersectionality* in diversity—differences within differences that make a difference (18).
86 Within any movement for equality and social justice, it is not uncommon for there to be blind spots
87 to the differences within a recognized group. As a result, individuals whose identities fall at the
88 intersection of classes seem to encounter doubly disparate access to care. To address these
89 intersections, networks of self-advocates living on the autism spectrum have created alliances with
90 disability-rights groups, LGBTQ alliances, and other movements for social justice and representation
91 (19).

92 As the view of ASD has changed over time, so has the need for providers and scientists to
93 communicate findings and recommendations around ASD. For example, erroneous reports of
94 vaccine-autism links have taken up significant energy and sowed confusion around causes of ASD,
95 although sites such as Vaccines Today are now providing high quality online communication and
96 vaccine information (20). Smaller qualitative studies (21) have described a journey of progressive
97 engagement with science for the parents of children diagnosed with ASD, whether to seek out
98 explanations to help them understand the condition or to seek appropriate/better services for their
99 children. A larger study in the US (22) comparing beliefs and understanding of parents and scientists
100 regarding ASD reported that there was significant discordance between parents and scientists on
101 their beliefs about causes of ASD and research priorities. In partial contrast, a large European study
102 (23) found that the autism community surveyed was generally supportive of autism research,

103 recommending that community perspectives be continually surveyed and considered in the design
104 of research studies, including the use of preferred terminology such as “at-risk” infants. We believe
105 that successful communication with families seeking information about ASD must include
106 interactive and inclusive messages and activities, welcoming multiple perspectives and tailoring
107 itself to formal or informal settings, and therefore designed our public engagement activity
108 accordingly. This may involve intentional inclusion of words or other documentation of views from
109 families that include a person with ASD, such as families from racial or ethnic backgrounds other
110 than the dominant culture (e.g., Latinx, African-American, recent immigrant, east-Asian, Indian);
111 families including parents and caregivers of many family structures; and people living on the autism
112 spectrum of differing genders, ages, and/or races. Luisi, Rodgers and Schultz (24) argued that
113 science communication requires training opportunities, which should include experiential learning,
114 and they pointed out that this type of training begs a framework for program evaluation.

115 Given our desire to communicate high-quality scientific information about ASD, we included
116 participation in multiple public events in the Dissemination and Outreach Core for our NIH-Funded
117 Autism Center of Excellence grant (NIMH 2P50 MH100029). Specifically, we sought to engage with
118 members of the public at a public science event, the Atlanta Science Festival, which closes with an
119 “Exploration Expo” attracting up to 30,000 people. Science festivals are becoming a more common
120 method for interaction with the public, including in areas of controversial science (25), and can be a
121 valuable tool for evaluating public engagement with scientific topics. Our booth, entitled “How Does
122 Your Brain Talk?”, offered both scientific information and a chance for passersby to answer specific
123 questions about possible knowledge gaps regarding ASD. The booth also included a visual exemplar
124 of brain development in the form of an animated portrayal of brain development research findings.
125 Such exemplars have been found to increase the impact of science communications about autism to
126 the general public (26). The booth was staffed by science trainees and junior faculty members who
127 had been communicating with the public for months in the context of tours of Marcus Autism
128 Center and were provided a one-hour seminar on how to approach the public, how to anticipate
129 and respond to “hot topics” that might reflect misinformation, and how to communicate key pieces
130 of information pertinent to the booth. To assess the experiential training aspect of working in the
131 booth, we asked questions of the individuals staffing the booth about their experience and its
132 anticipated impact on future science communication activities. As noted by Patton (27), a
133 qualitative analysis using a theme analysis is a common first step in program evaluation. We used
134 this type of analysis to evaluate the feedback from both groups of stakeholders: the attendees and
135 the booth staffers.

136 **Statement of Ethical Review**

137 The authors reviewed the purpose, design, execution and use of this project and determined that it
138 fit the definition of Program Evaluation as stipulated by Emory University
139 (<http://www.irb.emory.edu/forms/review/programeval.html>). The Emory University IRB’s Non-
140 Human Subjects Research Determination Electronic Form agreed that this project was exempt from
141 review by the university’s Institutional Review Board.

142 **Methods**

143 Terminology

144 In the larger community related to autism spectrum disorders, we see the terms autism and ASD
145 both used frequently. We also see “people with autism/ASD” and “autistic people” used and would
146 generally defer to the choice of the person involved. In this article, we will use all four of these
147 terms.

148 Booth setup

149 Our booth at the Atlanta Science Festival in March 2019 included a mock magnetic resonance
150 imaging (MRI) scanner, constructed from cardboard and a table, with sound effects for how an MRI
151 might sound through headphones. As part of the booth experience, attendees were able to lay on
152 the table and have the staffers, primarily students or faculty from the Marcus Autism Center, move
153 cardboard parts of the mock MRI above them while playing the sound effects and explaining how an
154 MRI takes pictures of the brain. [No research or evaluation were conducted or collected on this
155 completely voluntary part of the festival booth.] Afterwards (or separately if they chose not to try
156 the mock scanner), they would be shown a rotating brain image on a monitor, depicting the wiring
157 of circuits in the brain as found through neuroimaging studies at our Center. At the front of the
158 booth were flip charts as described below.

159 Data Collection

160 Data were collected to evaluate two aspects of the community outreach event. The first question of
161 what type of information would fit the needs of the audience at the event was evaluated by asking
162 two questions.

163 Question 1: “What would you like to know about autism?”

164 Question 2: “What would you like others to know about autism?”

165 These questions were posted atop two 20-inch by 23-inch flip charts in the display booth and on the
166 wall of the booth. Staffers directed attendees’ attention to the questions as they began interacting
167 with the display. Two corresponding methods were used to gather responses for both questions.
168 One consisted of the staffers in the booth transcribing oral responses from attendees onto the flip
169 charts where the questions were posted or asking the attendees to write their own response onto
170 the flip chart. The second method was to provide small self-adhesive note pads on which attendees
171 wrote their responses and posted them on the wall of the booth. We did not collect any
172 information about attendees and cannot match them to their comments. Following the event,
173 responses gather in both methods were transcribed into a single text file.

174 The second research question was how the staffers experienced the role of communicating with the
175 public and what (if anything) they learned. In order to gather this information, staffers were asked
176 to complete a questionnaire of four open-ended questions.

- 177 1. What was the main thing you learned from this experience?
- 178 2. How did you change what you were communicating over the course of the day?
- 179 3. What did you learn about people’s perception about autism or science in general?
- 180 4. What would you change about our efforts for next time?

181 The questionnaire was distributed via email eight days after the event, and one follow-up email
182 prompt was sent to those who had not responded after seven days. We did this anonymously and
183 coding was not able to match respondent to response.

184 Data Analysis

185 Responses from the event were analyzed using content analysis approach. This analytic approach
186 facilitated the conceptual organization of the attendee responses (28). Content analysis utilizes
187 deductive or inductive coding. The former coding technique purposefully codes for established set
188 of words, phrases, or concepts (29). Inductive coding develops concepts from the responses without
189 establishing codes a priori (29), and therefore was used for this evaluation. Once conceptual coding
190 was completed, patterns were identified, and the concepts were grouped into meaningful
191 categories. Frequently, content analysis involves quantifying coding categories and may retain only
192 the most prevalent (29). For this evaluation, all responses were retained for the final analysis. The
193 lead coder (CBS) developed the coding concepts and initial categories. For inter-coder reliability, a
194 second and third coder reviewed coding concepts and edited organization of the categories for
195 clarity. Consensus was reached for the final analysis. Given our small data set, we did not believe
196 utilizing a statistical measure for reliability was appropriate; our aim was 100% agreement.

197 As an additional means of analyzing themes in the responses from attendees, we analyzed the text
198 of the public responses using the Semantic Word Clouds Visualization tool (30,31). We produced
199 two separate visualizations: first (Figures 1A and 2A), we applied a simple layout of sorting by rank.
200 Number of words was set at 50. Similarity was determined by the cosine coefficient, ranking was by
201 term frequency, sizing was 4:3, and color was black. Second (Figures 1B and 2B), we used the layout
202 settings for the seam carving algorithm, which determines an image based on semantic
203 relationships and then minimizes the number of empty spaces between groups of words (31).
204 Number of words was set at 100. Similarity was also determined by the cosine coefficient, ranking
205 was by term frequency, sizing was 4:3, and color was ColorBrewer 2. In all figures, stop words and
206 numbers were removed, similar words were grouped, and the shortest word was set at three
207 letters.

208 **Results**

209 Approximately 150 attendees engaged with the booth during the event; 27 responses were
210 collected for Question 1 and 30 were collected for Question 2. The median length of response was
211 eight and nine words for Question 1 and Question 2 respectively. Attendees appeared to include
212 diversity in ages, gender, ethnic origin, and relationship to ASD; in discussion with the booth
213 staffers, attendees reported themselves to be from multiple professions and family situations.
214 Many passersby saw the name of the booth sponsor (Marcus Autism Center) and stopped by
215 specifically to tell us about their family member, student, patient, or friend with ASD. A few
216 individuals specifically self-identified as having ASD. Therefore, it is clear that from the general
217 audience who self-selected by attending a science festival, our evaluation participants represent a
218 subset with a much higher likelihood of interest in or personal relationship to ASD science.

219 Inductive content analysis of the attendees' responses to our questions revealed several prominent
220 themes. Overall, for Question 1, people appeared to be most interested in learning how ASD is
221 diagnosed or defined. There were also multiple questions about causes for ASD, including
222 environmental factors (but not including vaccines). Finally, specific treatment questions were
223 raised, including service locations in the area, transitioning from childhood to adulthood and
224 beyond, and diet or counseling requests.

225 For Question 2, the responses centered around educating those unaffected by ASD on how to
226 improve interactions and awareness and dispelling negative stereotypes. Specific advice on how to
227 treat them in the emergency room, for example, was mixed in with general advice such as "They

268 about ASD themselves, and to bring more awareness about ASD to the community. A number
269 expressed surprise at the intense level of interest in the science around ASD (and the enthusiasm of
270 children for trying out the mock MRI scanner), but confirmed that as scientists, they enjoyed
271 translating their scientific work and learning about the concerns and questions of those interested
272 in ASD but not working in a scientific setting. They reported changing their approach for science
273 communication based on the individual, sometimes focusing just on the brain and other times more
274 on ASD.

275 The staffers also made specific suggestions about the booth layout: more space was needed
276 because it became crowded at peak times, and a more sophisticated MRI scanner would be optimal.
277 There was some disagreement at the Festival about whether it is best to reach out to people
278 walking by instead of waiting for them to approach the booth, but in their responses, multiple
279 staffers said the next booth should feature more engaging activities or visuals, and the team should
280 plan to engage all passersby, perhaps with a short script. In keeping with an inclusive approach, one
281 staffer specifically asked for some items in Spanish to be created for the next time, because “I had a
282 few families come up to me who only spoke Spanish. I was able to translate for them, but they
283 wanted materials to take home with them and I would’ve loved to have provided them with
284 materials in Spanish.” Clearly, the prominent desire for next year was to include even more science
285 and allow for more in-depth conversations with interested parties.

286 **Discussion**

287 From the responses to our Question 1, “What would you like to know about autism,” the responses
288 most often included questions on how ASD is diagnosed or defined. This result is likely to be
289 affected by the theme of the booth, as it is related to a larger project to detect and diagnose ASD at
290 earlier ages, and therefore this theme was much more likely to be mentioned by the staffers
291 interacting with those entering the booth and interacting with them. In addition, we saw multiple
292 questions about the specifics of ASD symptoms and manifestations, whether behavioral, cognitive,
293 or social. These themes are likely influenced by the personal relationships many of our general-
294 public attendees disclosed, including as a teacher or nurse, for example. Family members of people
295 with autism were more likely to ask specific treatment queries, such as “Where can older children
296 get services in Atlanta, my daughter was diagnosed at age 13.”

297 Overall, the responses we received when we asked what people wanted to know about ASD reflect
298 larger questions in the community as a whole, based on our experiences interacting with the
299 community for multiple years as a researcher (CG) and clinician (DJ). How can we help children as
300 they transition into adulthood? What does scientific research tell us about ASD symptoms,
301 diagnoses, and treatments? What are the specific symptoms of ASD, and what do terms like “high-
302 functioning” mean? And what is new research, such as into the microbiome or the role of
303 pesticides, telling us about ASD?

304 We did not record any questions about vaccines, and none were written on the flip-chart boards or
305 Post-It notes. This suggests that either attendees asked those questions directly to booth staff (and
306 would have been told that there is no link between vaccines and autism), and/or that the public
307 who stopped by did not have this question or did not want to put it into writing.

308 For Question 2, on what others should know about autism, we saw many more references to
309 inclusivity and the more personal side of the condition. Overwhelmingly, respondents want to teach
310 those who are unaffected on appropriate ways to interact with individuals with ASD. This included

311 advice on patience and not “taking things personally,” as well as specifics like “think twice before
312 wearing cologne/perfume” due to sensory sensitivities. Respondents wanted to share the positive
313 attributes of people they knew with ASD and counter the idea that autism and intellectual disability
314 are conflated (four comments specifically mentioned that people with autism are “smart” or that
315 they “aren’t necessarily intellectually disabled!”).

316 Individuality of people with ASD was a prominent theme as well, echoing themes we have heard
317 from self-advocates for years like “Not all kids with autism look the same.” Simultaneously, there
318 was also a theme of request for inclusion, such as “We exist too,” “We’re not that different,” and
319 “Many people with autism are lonely....Can be good friends!”

320 Finally, we heard about the intersectionality of ASD with the experience of being a minority, from
321 comments like “Black autistic folk exist too.” We grouped this into a theme with requests for
322 “seeing” the autistic person, including other statements like “Just because they don’t ‘look’ autistic
323 doesn’t mean they aren’t.”

324 We conclude from our content analyses that the science festival brought multiple benefits to our
325 efforts to communicate with the public. At the same time, there is clearly value to the ASD
326 community in seeing themselves represented at such an event. Some self-identified autistic
327 individuals stayed for in-depth conversations and shared their experiences with us. Our staffers
328 reported they enjoyed learning from those with ASD too, and that they would use the experience to
329 shape future research and future interactions. In addition, their responses did seem to reflect
330 growth in science communication through expanded knowledge of public need and increased
331 repertoire for engaging with them. The greater variety of hands-on activities in the booth suggested
332 by staffers could function as multiple visual exemplars and thus support increased learning for
333 attendees (26). In future festival booths, we would also like to recruit some staffers or volunteers
334 who identify as being autistic themselves.

335 The primary limitation of this work is the difficulty in generalization from our findings, given its
336 nature as an evaluation of a one-time event. This evaluation may also provide guidance for future
337 research in this area. Data collection could be expanded either by repeating the same event as we
338 had planned to do (unfortunately, the 2020 Atlanta Science Festival was canceled due to the
339 coronavirus pandemic) or repeating this setup at another festival to increase the sample size. These
340 added events would allow a more refined analysis of responses and possible exploration of issues
341 related to intersectionality. Researchers might need to gather data from multiple events or in
342 multiple locations within a science fair to achieve this goal. Based on the themes derived from the
343 present evaluation, future research could formalize a set of information to be communicated to
344 meet the needs identified here; such studies should include a measure of efficacy in getting the
345 message across to members of the public. It also could be informative to include different methods
346 of communication (perhaps including different language translations) within a single event in order
347 to compare the efficacy of those methods. In addition, designing a study that gathered contact
348 information would allow researchers to follow-up and gather data about the durability of
349 information communicated to attendees. Each of these directions could further expand our
350 understanding of effective science communication.

351 **Conflict of Interest**

352 The authors declare that the research was conducted in the absence of any commercial or financial
353 relationships that could be construed as a potential conflict of interest.

354 **Author Contributions**

355 CG and DJ designed the evaluation and the questionnaires. CS completed the first round of coding,
356 and all authors participated in later iterations of analysis. All authors contributed to manuscript
357 revision, read and approved the submitted version.
358

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