

## **Interviewing silence: In conversation with the Autism Community**

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### **Abstract:**

Collecting an oral history of autism presents extraordinary challenges. A third of all autistic individuals are nonspeaking, many others are seriously speech impaired, and their parents are often so overwhelmed by the burdens of caring for disabled children that they have little time to reflect about their experiences. Moreover, the mainstream media likes ‘happy news’ about autism (e.g., fundraisers, job training programs) and prefers not to dwell on the dark side (neurological damage, unemployment, violent outbursts, suicide). Here I explain the methodology behind my article ‘The Autism Literary Underground’, published in the journal *Reception*. I conducted interviews by email, in part because scheduled audio-recorded interviews are likely to be interrupted by the daily crises that autism families face, such as meltdowns and elopements. I specifically interviewed a small cohort of autism parents about their reading and how it shaped their attitudes toward the disorder, and I compared their responses with the results of larger scale studies. What emerged was a self-portrait of the autism community that is very different from what the mass media presents.

**Keywords:** Email interviews; autism; reading; controversy

The blind and the deaf have always been with us, and over the centuries we have learned how to communicate with them. But autism is a relatively new (and increasingly common) disability, and we don’t yet understand it or know how to deal with it. The symptoms vary enormously from individual to individual. Severity can range from barely noticeable to totally debilitating. The condition often impairs the ability to read but can also result in ‘hyperlexia’, a syndrome which involves precocious reading at a very early age but also difficulties in reading comprehension.

In short, the autism epidemic confronts us with many more questions than answers. We might find those answers by interviewing members of the autism community, defined as including both autistic individuals and their family members, but there we run up against a

number of special obstacles. That is what I encountered when I conducted research for an article that was eventually published as 'The Autism Literary Underground',<sup>1</sup> and here I want to explain how we might work around these barriers.

For starters, about a third of autistic individuals are nonspeaking, and many others suffer lesser but still serious forms of verbal impairment. But at least some nonspeakers can communicate via a keyboard, and can therefore be reached via email interviews, which have a number of other advantages: they save the trouble and expense of travel and transcription, they avoid transcription errors and indistinct recordings, and they allow the interviewer to go back and ask follow-up and clarification questions at any time. This is not to rule out oral interviews, which are indispensable for the nonliterate. But email interviews are generally easier for autism parents, who are preoccupied with the demands of raising disabled children, many of whom will never be able to live independently. These parents simply cannot schedule a large block of time for a leisurely conversation. When I conducted my interviews, the interviewees often had to interrupt the dialogue to attend to their children. Perhaps the most frequent response to my questions was, 'I'll get back to you....' (One potential interviewee was never able to get back to me, and had to be dropped from the project.) Ultimately these interviews addressed all the questions I wanted to address and allowed interviewees to say everything they had to say, but in email threads stretching over several days or weeks.

Recent decades have seen a movement to enable the disabled to 'write their own history'. In 1995 Karen Hirsch published an article advocating as much in *Oral History Review*, in which she discussed many admirable initiatives focusing on a wide range of specific disabilities – but she never mentioned autism.<sup>2</sup> Granted, autism was considerably less prevalent then than it is today, but the omission may reflect the fact that autism presents special problems to the researcher. In 2004 the Carlisle People First Research Team, a self-governing group for those with 'learning difficulties', won a grant to explore 'advocacy and autism', but soon concluded that their model for self-advocacy did not work well for autistic individuals. Though the Research Team members were themselves disabled, they admitted that they knew little about autism, and 'there was an obvious lack of members labelled with autism or Asperger's syndrome' in disability self-advocacy groups throughout the United Kingdom. The Research Team concluded that, because autism impairs executive functioning as well as the ability to socialize and communicate, it was exceptionally difficult for autistic individuals to organize their own collective research projects, and difficult even for non-autistic researchers to set up individual interviews with autistic subjects.<sup>3</sup>

Self-advocacy groups do exist in the autism community, but they inevitably represent a small proportion at the highest-performing end of the autism spectrum: they cannot speak for those who cannot speak. We can only communicate with the noncommunicative by interviewing their families, who know and understand them best.

One also has to be mindful that the autism community is riven by ideological divisions, and the unwary researcher may be caught in the crossfire. For instance, if you invite an autistic individual to tell his own story, he might say something like this:

As a child, I went to special education schools for eight years and I do a self-stimulatory behavior during the day which prevents me from getting much done. I've never had a girlfriend. I have bad motor coordination problems which greatly impair my ability to handwrite and do other tasks. I also have social skills problems, and I sometimes say and do inappropriate things that cause offense. I was fired from more than 20 jobs for making excessive mistakes and for behavioural problems before I retired at the age of 51. Others with autism spectrum disorder have it worse than I do. People on the more severe end sometimes can't speak. They soil themselves, wreak havoc and break things. I have known them to chew up furniture and self-mutilate. They need lifelong care.<sup>4</sup>

This is an actual self-portrait by one Jonathan Mitchell, who is autistic. So you might conclude that here we have an excellent example of the disabled writing their own history, unflinchingly honest and compassionate toward the still less fortunate, something that everyone in the autism community would applaud. And yet, as Mitchell goes on to explain, he has been furiously attacked by 'neurodiversity' activists, who militantly deny that autism is a disorder at all. They insist that it is simply a form of cognitive difference, perhaps even a source of 'genius', and they generally don't tolerate any discussion of curing autism or preventing its onset. When Mitchell and other autistic self-advocates call for a cure, the epithets 'self-haters' and 'genocide' are often hurled at them. So who speaks for autism? An interviewer who describes autism as a 'disorder', or who even raises the issues that Mitchell freely discussed, might well alienate a neurodiversity interviewee. But can we avoid those sensitive issues? And even if we could, should we avoid them?

Mitchell raises a still more unsettling question: Who is autistic? The blind, the deaf, and the wheelchair-bound are relatively easy to identify, but autism is defined by a complex constellation of symptoms across a wide spectrum – and where does a spectrum begin and end? You could argue that those with a formal medical diagnosis would qualify, but what about those who are misdiagnosed, or mistakenly self-diagnosed? What if their symptoms are real but extremely mild: would an oral historian researching deafness interview individuals with a 10 percent hearing loss? Mitchell contends that neurodiversity advocates cluster at the very high-functioning end of the spectrum, and suspects that some aren't actually autistic:

Many of them have no overt disability at all. Some of them are lawyers who have graduated from the best law schools in the United States. Others are college professors. Many of them never went through special education, as I

did. A good number of them are married and have children. No wonder they don't feel they need treatment.<sup>5</sup>

Precisely because neurodiversity advocates tend to be highly articulate, they increasingly dominate the public conversation about autism, to the exclusion of other voices. Mitchell points to the Interagency Autism Coordinating Committee, an official panel that advises the US government on the direction of autism research: seven autistic individuals have served on this body, all of whom promote neurodiversity, and none favor finding a cure. The most seriously afflicted, who desperately need treatment, are not represented, and they 'can't argue against 'neurodiversity' because they can't articulate their position. They're too disabled, you might say.'

The severely disabled could easily be excluded from histories of autism, unless the researcher makes a deliberate effort to include them, and in many cases we can only include them by interviewing their families. My own research relied on email interviews with self-selected respondents to a call for participants I had posted on autism websites. Though I made clear that I wanted to communicate with autistic individuals as well as with other members of their families, only the latter responded. As Jan Walmsley has rightly pointed out, consent is a thorny issue when we interview the learning disabled.<sup>6</sup> I specified that I would only interview responsible adults – that is, those who were not under legal guardianship – but that proviso effectively excluded a large fraction of the autism community. For researchers, that may present an insurmountable difficulty.

Yet another ideological landmine involves the causes of autism, for many in the autism community believe it is a disorder that results from adverse reaction to vaccination. In my own research, this was the group I chose to focus on. The mainstream media generally treat them as pariahs and dangerous subversives, denounce them repetitively, and almost never allow them to present their views. But that kind of marginalization inevitably raise troubling questions: Are these people being misrepresented? What is their version of events? And since they obviously aren't getting their ideas from the newspapers or television networks, what exactly are they reading, and how did that reading shape their understanding of what has been inflicted on them? So I started with a simple question: What do you read? Unsurprisingly, many of my subjects had read the bestselling book *Louder Than Words* (2007) by actress Jenny McCarthy, where she describes her son's descent into autism and argues that vaccination was the cause. Doctors have expressed horror that any parent would follow medical advice offered by a *Playboy* centerfold, but a historian of reading might wonder whether the reader response here is more complicated. Are readers 'converted' by books, or do they choose authors that they already sympathize with? My interviewees reported that, well before they read *Louder Than Words*, they had seen their children regress into autism immediately following vaccination. They later read Jenny McCarthy out of empathy, because she was a fellow autism parent struggling with the same battles that they had to confront every day.

Granted, my sample was quite small, essentially a focus group of just six self-selected parents. Occasionally oral historians can (through quota sampling) construct large and representative surveys, for instance Paul Thompson's landmark 1975 study of Edwardian Britain,<sup>7</sup> but it would be practically impossible to do the same for the fissured and largely nonspeaking autism community. What oral historians can sometimes do is to crosscheck their findings against large statistical surveys. For instance, my respondents said that they read Jenny McCarthy not because she was a celebrity, but because she was an autism mom. They were corroborated by a poll of 1552 parents, who were asked whom they relied for vaccine safety information: just 26 percent said celebrities, but 73 percent trusted parents who reported vaccine injuries in their own children.<sup>8</sup> To offer another illustration: vaccine skeptics are often accused of being 'anti-science', but my interviewees produced lengthy bibliographies of scientific journal articles that had shaped their views. They were supported by a survey of 480 vaccine skeptic websites, of which 64.7 percent cited scientific papers (as opposed to anecdotes or religious principles).<sup>9</sup>

A careful reader of this article will note that, at the outset, I described autism as an 'epidemic'. This is yet another flashpoint of controversy. Public health officials generally avoid the word, and many journalists and neurodiversity activists fiercely argue that autism has always been with us. As a historian who has investigated the question, I have concluded (beyond a reasonable doubt) that autism scarcely existed before the twentieth century, and that it is now an ever-spreading pandemic. To explain the evidence behind this conclusion would require a very long digression, though I can refer the reader to a robust demonstration.<sup>10</sup> The essential point here is that any interviewer who refers to autism as an 'epidemic' may alienate some of his interviewees.

So how do we handle this situation – or, for that matter, any other divisive issue? All oral historians have opinions: we can't pretend that we don't. But we can follow the ethic of an objective reporter. A journalist is (or used to be) obligated to report all sides of an issue with fairness, accuracy, and balance. He may personally believe that one side is obviously correct and the other is talking nonsense, but in his professional capacity he keeps those opinions to himself and assures his interviewees that they are free to express themselves. One has to accept that not everyone will be reassured. I found myself variously accused of being (on the one hand) an agent of the pharmaceutical companies or (on the other) an anti-vaccinationist. (I am neither.) But most of my subjects were quite forthcoming, once I made clear that the article I was writing would neither endorse nor condemn their views.

Of course, if any of the voices of autism are stifled, then the true and full story of the epidemic will be lost. Some honest and well-researched histories of autism have been produced, notably Chloe Silverman's *Understanding Autism*<sup>11</sup> and Edith Sheffer's *Asperger's Children*.<sup>12</sup> Although Silverman only employs a few interviews, her work is distinguished by a willingness to listen closely to autism parents. And in her chilling account of the Nazi program to eliminate the mentally handicapped, Sheffer uncovered the voices of some of its autistic victims in psychiatric records. What both these books suggest is that we could learn much more about autism as it was experienced by ordinary people, simply by talking to

them. Many of them protest that the media only reports ‘happy news’ about autism (e.g., fundraisers, job training programs) and prefers not to dwell on the dark side (neurological damage, unemployment, violent outbursts, suicide), and these individuals are usually eager to tell their stories. To take one striking example, in 2005 the *New York Times* dismissed the theory that thimerosal (a mercury-containing preservative in some vaccines) might cause autism in a 2005 front-page story headlined ‘On Autism’s Cause, It’s Parents vs. Research’ (suggesting that parents did no research).<sup>13</sup> One of my interviewees had herself been interviewed by Gardiner Harris, one of the reporters who filed the *Times* story, and she offered a very different version of events:

Harris misidentified one of the two women in his opening anecdote. He described an autistic child’s nutritional supplements as ‘dangerous,’ though they had been prescribed by the Mayo Clinic for the child’s mitochondrial disorder – facts he did not disclose. Three times Harris asked me, ‘How do you feel?’ rather than, ‘What scientific studies led you to believe thimerosal is harmful to infants?’<sup>14</sup>

Rather than rely solely on ‘the newspaper of record’ (or any other newspaper), historians can find correctives and alternative narratives in oral interviews. Oral history has made an enormous contribution to reconstructing the history of the AIDS epidemic and the opioid epidemic, and it will be no less essential to understanding the autism epidemic.

### **Biographical Note:**

Jonathan Rose is William R. Kenan Professor of History at Drew University. He was the founding president of the Society for the History of Authorship, Reading and Publishing and was a long-standing editor of the journal *Book History*. His book *The Intellectual Life of the British Working Classes* (2<sup>nd</sup> ed., 2010) won the Longman-History Today Historical Book of the Year Prize, the American Philosophical Society Jacques Barzun Prize in Cultural History, the British Council Prize of the North American Conference on British Studies, the SHARP Book History Prize, and the New Jersey Council for the Humanities Book Prize. His other publications include *The Edwardian Temperament 1895-1919*, *The Holocaust and the Book: Destruction and Preservation*, and *The Literary Churchill: Writer, Reader, Actor* (winner of the New Jersey Council for the Humanities Book Award for Scholarly Humanities Non-Fiction). With Simon Eliot, he will soon publish a second expanded edition of *A Companion to the History of the Book*. He is now editing (with Mary Hammond) *The Edinburgh History of Reading*. In 2018 Oxford University Press published his latest book, *Readers’ Liberation*. Contact: [jerose@drew.edu](mailto:jerose@drew.edu).

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<sup>1</sup> Jonathan Rose, 'The Autism Literary Underground,' *Reception: Texts, Readers, Audiences, History* 9 (2017): 56-81.

<sup>2</sup> Karen Hirsch, 'Culture and Disability: The Role of Oral History,' *Oral History Review* 22/1 (Summer 1995): 1-27.

<sup>3</sup> Louise Townson, Sue Macauley, Elizabeth Harkness, Andy Docherty, John Dias, Malcolm Eardley, and Rohss Chapman (2007) 'Research project on advocacy and autism', *Disability & Society*, 22:5, 523-536.

<sup>4</sup> Jonathan Mitchell, 'The Dangers of 'Neurodiversity': Why Do People Want to Stop a Cure for Autism Being Found?' *Spectator* (19 January 2019).

<sup>5</sup> Ibid.

<sup>6</sup> Jan Walmsley, 'Life History Interviews with People with Learning Disabilities,' in *The Oral History Reader*, 2<sup>nd</sup> ed., ed. Robert Perks and Alistair Thomson (London and New York: Routledge, 2006), 184-97.

<sup>7</sup> Paul Thompson, *The Edwardians: The Remaking of British Society* (Chicago: Academy Chicago, 1985).

<sup>8</sup> Rose, 'Autism Literary Underground,' 73-74.

<sup>9</sup> Ibid., 66.

<sup>10</sup> See Dan Olmsted and Mark Blaxill, *Denial* (New York: Skyhorse Publishing, 2017).

<sup>11</sup> Chloe Silverman, *Understanding Autism: Parents, Doctors, and the History of a Disorder* (Princeton: Princeton University Press, 2011).

<sup>12</sup> Edith Sheffer, *Asperger's Children: The Origins of Autism in Nazi Vienna* (New York: W. W. Norton, 2018).

<sup>13</sup> Gardiner Harris and Anahad O'Connor, 'On Autism's Cause, It's Parents vs. Research,' *New York Times*, June 25, 2005, A1.

<sup>14</sup> Rose, 'Autism Literary Underground,' 75.