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Still infantilizing autism? An Update and Extension of Stevenson et al. (2011)

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Abstract

Background: Stevenson et al. (2011) examined photographs and language used to represent autism on chapter websites for the Autism Society of America, autism charity websites, movies, television shows, fictional books, and U.S. news stories, and found that they overwhelmingly used children to represent autism.

Methods: Using Stevenson et al.'s methods, we tested the hypothesis that, a decade on, these same sources would now include more representations of autistic adults. We statistically compared our findings to theirs.

Results: On the chapter websites of the Autism Society of America and in fictional books, the hypothesis was supported in that there were more representations of adults (20%) than in the original study (5%), but there were still far more representations of children than of adults. In movies, television shows, and U.S. news stories, there were equal numbers of representations of autistic adults and autistic children.

Conclusions: These findings suggest a move away from infantilizing autism in some domains, but they rely on a narrow construal of "infantilizing": the underrepresentation of autistic adults in media. However, even when autistic adults are represented, they may still be infantilized in various ways. Future research will need to examine the impact of infantilizing media on both autistic and non-autistic people, and other ways in which these representations are limited (e.g., gender and race/ethnicity).

Community Brief

Why is this an important issue?

A prior study showed that most representations of autistic people in the U.S. portray children. It is important that the public not perceive autism as a disability that only affects children. If autistic adults are not adequately represented, they and their needs become invisible.

What was the purpose of this study?

We wanted to see if representations of autistic adults in U.S. have increased in the decade since the original study was published.

What did the researchers do?

We counted the numbers of representations of autistic adults and autistic children on the chapter websites of the Autism Society of America, autism charity websites, in fictional books, movies, and television shows with autistic characters, and in U.S. news stories that mentioned autistic people. We then compared these numbers to the numbers from the original study.

What were the results of the study?

On the chapter websites of the Autism Society of America and in fictional books, there were more representations of adults than in the original study, but there were still far more representations of children than of adults. In movies and television shows, as well as U.S. news stories, the number of representations of autistic adults was equal to those of children.

What do these findings add to what was already known?

These findings show there has been some progress in increased representations of autistic adults in the U.S. Our study cannot tell us what exactly has contributed to this change, but we speculate that the rise of autistic self-advocacy is the most likely candidate, as it has trickle-down effects such as hiring of autism consultants for movies and TV shows and journalists' increased use of autistic self-advocates as sources.

What are potential weaknesses in the study?

Our analyses, like the original study, are limited to depictions of autism in the U.S. and examine only one aspect of representation (age). Gender and race/ethnicity of autistic representations need to be examined in future research.

How will these findings help autistic adults now or in the future?

Knowing about representation of autistic adults is important because of the many potential benefits of accurate representation, such as access to accommodations and resources beyond childhood (e.g., jobs, healthcare). Positive media representations may also help reduce stigma and stereotypes.

Introduction

What we now call autism began as infantile autism, but never forget that autism is for life.

- Ian Hacking (2009, p. 46)¹

Autism is usually diagnosed in childhood and tends to be represented by the faces of children. Stevenson and colleagues conducted content analyses of a variety of websites and media sources pertaining to autism and found that a prominent parent-run organization, charitable organizations, news and other popular media (books, films, and TV shows) all overwhelmingly used images and descriptions of children to represent autism.² Since that study was published, there has been an increase in the number of studies including autistic adults as participants,^{3,4} a new journal focusing only on autistic adults (*Autism in Adulthood*, established 2019), and even a think tank focused on autistic aging.⁵ However, the overwhelming majority of autism research continues to focus on children.⁶ Meanwhile, large numbers of autistic children diagnosed in the 1990s and 2000s have transitioned into adulthood, creating a pressing need for adult-focused research, services, advocacy, and policy.⁴ The need for research on, and resources for, autistic adults is undeniable; however, the “invisibility” of autistic adults may make it harder to argue for these resources. The research question we address in this study is whether representations (images and descriptions) of autistic individuals have changed to include more adults a decade after Stevenson et al.’s study.

To address this question, we conducted the same content analyses as Stevenson et al. and compared their results with ours to test the hypothesis that representations of adult autistics have increased in the past decade. The rationale for this hypothesis involves two interrelated developments: the neurodiversity movement and the rise of autistic self-advocacy.

Still infantilizing autism?

Neurodiversity, the idea, states that some neurocognitive differences that are taken to be disorders, such as autism, should be understood as forms of human diversity and should not be pathologized.⁷ This idea is at the heart of neurodiversity, the social-political movement.

Proponents of the neurodiversity movement, as it applies to autism, argue that autism is an aspect of identity that should be respected and accommodated, and certainly not eliminated.^{8,9} Many (if not most) autistic self-advocates endorse the idea of neurodiversity and support the neurodiversity movement's perspectives and commitments.^{10,11}

Awareness and acceptance of the neurodiversity framework is increasing both inside and outside of the academy, due in large part to the efforts of autistic self-advocates,^{12,13} some of whom conduct autism research.¹⁴ Autism Network International (ANI) was the first formal group created by and for autistic adults.^{10,15} It provided a space for autistic people to meet, to see themselves as having their own unique culture and identity,¹⁶ and to begin to advocate for themselves. For example, Jim Sinclair, one of the founders of ANI, wrote an oft-cited speech urging non-autistic parents to love their autistic children for who they are and to not try to rid them of their autism;¹⁷ this speech is seen as having played a very important part in establishing the foundations of the neurodiversity movement.¹⁸ Websites with discussion forums dedicated to issues faced by autistic people also contributed to connecting autistic individuals with one another, providing a shared sense of struggle¹⁹ and educating non-autistic people about their perspectives.²⁰

The currently most influential advocacy group is The Autistic Self Advocacy Network (ASAN) that was founded in the U.S. in 2006. They have been credited with changing the national conversation on autism¹³ by writing and organizing for inclusion in that conversation with the slogan "Nothing About Us Without Us." In a recent content analysis of *Washington*

Post articles about autism, researchers suggest that ASAN has been instrumental in educating both journalists and the public about neurodiversity, which has led to an increase in positive depictions of autism.¹²

Because self-advocates are generally adults, it is possible that they have also played a role in changing the stereotyped image of autism as associated with children. Stevenson et al.'s analyses indicated that the overwhelming majority of depictions of autism—on websites, in fictional books, news articles, films, and television shows—involved the faces of children.² The current study conducted the same content analyses as Stevenson et al. decade on to see if any progress has been made towards including more depictions of autistic adults. We present each content analysis in the same order as Stevenson et al., labeling them as separate studies for ease of presentation, and compare our results with theirs. In some cases, we conducted additional analyses pertinent to our hypothesis: e.g., examining whether websites contained links to resources for autistic adults.

Study 1: The Autism Society of America

The Autism Society of America is a national organization founded in 1965 by clinicians and parents of autistic children. Stevenson et al. hypothesized that, given these origins, it would be motivated to represent autism as a childhood disability and hence be very likely to infantilize autism. At the time of our analyses, their “About Us” page stated they were “proud to be one of the few organizations to have members on the autism spectrum serving as active members of our board directors as well as in other leadership positions throughout the organization.”

Moreover, many of the children of the parents and grandparents who help run the Autism Society of America are now adults, which may have motivated the leadership to increase the

representation of autistic adults. As such, we hypothesized that this organization might do better now at displaying photographs of autistic adults than it did in 2009 when Stevenson et al. conducted their coding—at that time, only 16% of chapters included any photographs of autistic adults (one photograph of an adult on each of a total of 8 chapter websites).

Method

In June of 2019, this organization's website (<https://www.autism-society.org/>) linked to 80 state and regional chapters, located in 37 states. We manually coded all photographs displaying single individuals (for photos with multiple people, it could not be assumed that all were autistic) on the homepages of these chapters. As in Stevenson et al., chapters were excluded if (a) they did not have an active website ($n = 4$) or (b) their homepage did not display any photographs of single individuals ($n = 27$); thus, a total of 49 homepages were inspected for photographs of single individuals (these photographs had to include the head of the individual). We excluded photographs of single individuals if they were clearly marked as being a staff person/clinician, parent, or celebrity. The first author identified 148 photographs that contained the head of a single individual and then she and an independent coder (who had been trained on photographs on websites not related to the study) classified the individual in each of these photographs as a child or an adult. To avoid biasing the data in favor of the hypothesis, individuals who appeared to be neither young children nor adults (i.e., young adolescents) were coded as children. The two coders achieved 100% agreement on this binary coding of photographs.

The first author also coded the resources pages of all 76 websites for whether they listed any resources specifically for adult autistics (yes or no) and searched for the terms *child* and *adult* to categorize each website as referring to children only or to both children and adults (no

website referred to adults only, and two sites mentioned neither children nor adults, but used the more generic terms “individuals” and “people on the spectrum”). As this coding did not involve potentially subjective judgments, simply a yes/no judgment on the presence of the terms *child* and *adult*, no reliability coding was conducted.

Results

Table 1 displays the number of child and adult photographs appearing on the homepages of the 49 state and regional chapters of the Autism Society of America that contained photographs of single individuals. Of the 148 photographs of individuals, 29 (20%) were of adults, compared to 8 (5%) in Stevenson et al.; $\chi^2(1, N=149) = 14.07, p < 0.05$. While this represents a statistically significant increase in representation of autistic adults in line with our hypothesis, it is still the case that the overwhelming majority of photographs (80%) of single individuals represented children. This percentage is far greater than what would be predicted by chance (50%), $\chi^2(1, N=149) = 55.58, p < 0.0001$.

Most sites (84%) used discourse referencing both children and adults, and the majority (87%) included links to resources for autistic adults. These measures were not included in Stevenson et al. so we cannot make a direct comparison. So, although the representation of autism in photographs on Autism Society of America’s chapter websites still seems to be slanted towards children, there are now more representations of autistic adults and acknowledgment (by explicitly mentioning them and including links to resources for them) of their needs.

Study 2: Charitable Organizations

The use of depictions of children for fundraising is a widespread practice²¹ based on the tendency of viewers to feel more empathy for unfamiliar children than they do for unfamiliar

adults.²² Charitable organizations tend to use this strategy, even as they recognize it as ethically problematic, because there is considerable evidence of its effectiveness.²³ As Stevenson et al. observed, charitable organizations raising funds for autism also tend to use images of children.

Beyond trying to increase empathy, several factors would seem to reinforce this practice. The pathologizing of autism incentivizes the search for causes and cures to prevent and eliminate autism.²⁴ The suspicion and fear that increased prevalence of autism is evidence of an autism epidemic would seem to further incentivize the search for causes and cures.²⁵ A few related developments since Stevenson et al. might lead one to expect that representations at charitable organizations have changed to include more adults. First, a large number of autistic children that these organizations focused on have transitioned into adulthood in the last decade. Second, there has been a corresponding increase in self-advocacy among autistic people.¹⁰ Third, much of this advocacy is informed by the neurodiversity perspective, which shifts away from pathologizing autism and a search for causes and cures towards research advances, services, and policy designed to support lifelong autistic flourishing into and throughout adulthood.¹⁰ Thus, we hypothesized a significant decrease in the use of images of children by the charitable organizations studied by Stevenson et al.

Method

Stevenson et al. identified 12 tax-exempt, nonprofit autism-related organizations that had reported over \$200,000 in revenue between June 2008 and June 2009. They examined the homepages, “About Us” pages, mission statements, donation entreaties, and explicit definitions of autism of these 12 charities and coded the language on these pages as either about children only or about children as well as adults (by searching for the terms *child* and *adult*). We aimed to code the same websites but ended up coding only eight because four were no longer active. One

organization's name had changed (from Autism International Association, Inc to AutismOne); its new website was included. One organization (Autism Family Foundation of Northeast Ohio) had closed, and three organizations' websites (Autism Consortium, Inc., Utah Autism Foundation, Childhood Autism Foundation, Inc) were no longer active in 2019. In addition to coding the discourse on these sites, we also examined the photographs of single individuals on their homepages and coded them as we did in Study 1.

In an additional analysis, we identified the top 12 charities in terms of revenue in 2019 from Charity Navigator's website using the search terms "autism" and "autistic" and their size filter. The results included 4 of the charities examined by Stevenson et al. (Autism Speaks, Inc., Autism Society of America, Organization for Autism Research, and the Doug Flutie Jr. Foundation for Autism). The other 8 included Southwest Autism Research and Resource Center, Turning Pointe Autism Foundation, The Asperger-Autism Network, Autism Spectrum Disorder Foundation, NEXT for Autism, Have Dreams, and Autism Research Institute.

Results

Table 2 displays the data for the 8 charities examined by Stevenson et al. Given the low frequencies, we did not conduct statistical analyses on these data. Five of the eight websites used discourse that referenced both adults and children, compared to three of the same websites coded by Stevenson et al. Two of the charities had no photos of single individuals on their homepages. Of the six that did, four only depicted children, and two depicted both adults and children. As with the Autism Society of America websites, these findings suggest a move in the direction of more representations of adult autistics, but most of the websites still tend to use children to represent autism. Although we need to be cautious in drawing conclusions as the number of non-profits (8) was reduced from those included in Stevenson et al. (12), it is interesting that 7 of the

8 charities that were among the top 12 in revenue in 2019 that were not included in Stevenson et al.'s analyses used discourse that referenced both children and adults. Only the Autism Spectrum Disorder Foundation referenced only children. Most of these websites did not include photos of the faces of single individuals.

Study 3: Popular Media

Popular media are a key socializing agent²⁶ and thus may influence public perception and attitudes about what is represented. Many people get their understanding of autism from popular media representations.^{27,28} And, of course, popular media are part of the cyclical pattern of influence that contributes to how autism is represented elsewhere.²⁹

A few related factors might lead one to expect that popular media representations of autism may have changed to include more adults since Stevenson et al.'s original study. First, as noted earlier, there has been an increase in self-advocacy by autistic adults and an accompanying spread of the neurodiversity perspective. Second, in keeping with the idea that there is a cyclical pattern of influence between various outlets of autism representations, national and charity organizations may be sources of information for popular media representations. As such, we reasoned that if there has been an increase in the number of adult representations at these organizations, then we might expect a trickle-down effect in representations of autism in popular media. However, it is more likely that increasing exposure to autistic advocates (who tend to be adults) may be influencing media portrayals of autism. Thus, we expect that the demand for and/or interest in popular media featuring autistic adults may have increased as the population of autistic adults (especially advocates) has increased.

Method

Films and TV shows. On July 13, 2019, a search of IMDB.com by the third author for the keyword “autism” for films released in 2010 or later yielded 289 titles. She removed 19 titles that had not yet been released (were in production or post-production) and added 56 titles from a search of Wikipedia for autistic fictional characters in films and TV shows released 2010-2019. The IMDB and Wikipedia lists were combined, and 24 duplicate titles were removed. In consultation with the second author, she also excluded documentaries, news/talk/reality shows, video games, charity events, advertisements, and four 2010 titles that had been included in Stevenson et al.’s original analysis (Stevenson et al. also included movies from Fancast; this website no longer exists). This left 176 titles; the plot summaries of 52 titles did not mention autism or Asperger’s and were removed, leaving a total of 124 titles.

The first author then coded the age of the autistic character from the plot summaries on IMDB.com. Wherever there was precise age information, 18 years and above was coded as **adult**. The words *man/woman/adult* or the name of any profession (e.g., doctor) in reference to the autistic character were coded as **adult**. The words *child/boy/girl/teen/son/daughter* in reference to the autistic character without further age info were coded as **child**. (A teen could of course be a child or an adult but, without precise age information, we coded *teen* as **child** so as not to bias the data in favor of the hypothesis.) If age information was not available in the IMDB plot summary, the Wikipedia plot summary (if available) was coded.

Fictional books. The advanced search feature on Amazon.com was used by the second and third authors to identify fictional books with the keywords *autism*, *autistic*, and *Asperger’s* from 2010 through 2017. All English-language paperbacks listed under the categories of

“Literature and Fiction,” “Children’s Books,” and “Teens and Young Adults” were included in a first pass and resulted in a total of 2350 results. Many of these results included collections of poetry, memoirs, activity/workbooks, and other works that were not fiction (N = 1264); these were excluded along with duplicate titles, yielding an initial sample of 1086 books. Also excluded were books whose descriptions did not contain information about an autistic character and books that had been included in Stevenson et al.’s data (N = 602). Thus, a total of 484 books’ descriptions were coded by the first author for the age of the autistic character, using the same criteria as in the analysis of films and TV shows. The age of the autistic character was not clear in the description of 8 books, and two books had both child and adult autistic characters; these 10 books were not included in the analyses.

Results

The films and television programs did not show a bias toward infantilizing autism; 72 (58%) of the autistic characters portrayed in the 124 film and television story lines were children, which is not different from chance; $\chi^2 (1, N = 124) = 3.23, p = 0.07$. This contrasts with Stevenson et al. who found that 68% of the autistic characters in the films and television shows they coded were children, a value that was statistically greater than chance. Thus, it appears that films and television shows in the past decade have included more adult autistic characters. However, a direct comparison between our findings and those of Stevenson et al. showed that the difference was not statistically reliable, $\chi^2 (1, N = 207) = 1.86, p = 0.18$.

The analysis of fictional books showed that overall, 81% of the characters in the 474 books coded were children, which is significantly different from chance, $\chi^2 (1, N = 474) = 179.88, p < 0.00001$, and significantly different from Stevenson et al.’s finding of 91%, $\chi^2 (1, N = 579) = 5.59, p = 0.02$. Thus, while overall there has been a decrease in the percentage of child

characters, the vast majority of characters are still children. There was no significant decrease in this percentage over the years included in the current study; 84% of books had child characters the first two years of the period under investigation (2010-2011) and 74% had child characters in the most recent two years (2016-2017). This difference was not statistically reliable, $\chi^2(1, N = 233) = 1.28, p = 0.26$.

Finally, we examined whether the percentage of child characters differed depending on book category as it is reasonable to expect more child characters in books written for children. Not surprisingly, nearly all (98%) of the characters in children's books were children. Only 67% of the characters in books classified under "Literature and Fiction" were children. This percentage is significantly different from chance, $\chi^2(1, N = 251) = 27.45, p < 0.001$, and from the percentage in children's books, $\chi^2(1, N = 446) = 68.38, p < 0.001$, indicating that books targeted at adults were more likely to have adult autistic characters than books targeted at children but still more child than adult characters.

These findings suggest that there has been a move in the direction of more representation of adult autistics in popular media. In the films and television shows we coded, there was equal representation of child and adult autistics, but in the books (especially children's books but even in fiction books for adults), there were still far more child characters than adult characters. On average, 75-85% of autistic characters portrayed in fictional books tended to be children.

Study 4: U.S. News Industry

Compared with parent-run organizations, charitable organizations, and the popular media, the news industry offers the most current depictions. Stevenson et al. hypothesized that news articles would perpetuate the infantilization of autism present in other sources of information.

However, a recent analysis of *Washington Post* articles about autism between 2007 and 2016 revealed later articles were more likely to contain a neurodiversity perspective and more likely to be positively valenced than earlier articles.¹² Furthermore, several organizations have recently adopted new guidelines about how to write about disabilities, including autism. More specifically, these guidelines now permit the use of identity-first language (e.g., autistic person) which is in line with the disability community's preference.³⁰⁻³² Finally, journalists are also recommended to use disabled people as sources, not just as characters in inspirational or medical stories.³³ Due to these shifting perspectives, we hypothesized that the news industry might now include more representations of autistic adults in their news stories.

Method

A Google search was conducted of news articles published during the one-month period of April 23, 2020 to May 23, 2020 exactly 10 years after Stevenson et al.'s analysis. The search term "autism" was entered into Google's main search bar and then filtered for news results using a custom range under tools. To maximize the number of hits, the search was repeated for one day at a time during the one-month period. The day was selected at random until all news articles had been entered. Google's algorithm changed since Stevenson et al. conducted their analysis. Searching for a one-month period cut off some of the results. Additionally, search results changed over time, most likely due to advertisements. To address these changes, searches were performed for one day at a time (to maximize the number of results) in a random order (due to fluctuations in results). This procedure identified 665 articles. News articles were excluded if (a) they were behind a paywall (n = 6); (b) they did not include the name of an autistic individual (n = 395); (c) the source was not associated with a print, television, or radio news outlet (n = 54);

(d) the source was not based in the U.S. ($n = 70$); (e) they included multiple autistic individuals ($n = 20$); or (f) they were duplicate articles ($n = 20$).

The remaining 100 articles were examined for the age of the autistic individual mentioned. Age was coded from text of the news articles as in Study 3. Wherever there was precise age information, 18 years and above was coded as **adult**. If education level was mentioned, college and higher was coded as **adult**. The words *man/woman/adult* or the name of any profession (e.g., doctor) were coded as **adult**, whereas the words *child/boy/girl* were coded as **child**. An additional two articles were excluded because the age of the autistic individual could not be determined, leaving a final sample of 98.

Results

Fifty-eight (59%) of the 98 news articles featured stories about autistic children, which is not different from chance, $\chi^2(1, N = 98) = 2.94, p = 0.09$. This contrasts with Stevenson et al. who found that 79% of the U.S. news articles featured autistic children, which was statistically greater than chance. Thus, the U.S. news industry has included significantly more news stories about autistic adults in the last decade, $\chi^2(1, N = 229) = 10.15, p = 0.001$. However, similar to Stevenson et al., approximately one-third (15/40) of the news articles that featured autistic adults also mentioned the parent of the autistic adult. Therefore, these findings suggest that while the U.S. news industry has moved in the direction of greater representation of autistic adults, it continues to infantilize these adults by referring to them as the children of non-autistic adults. In the Discussion, we return to this aspect of infantilizing autism and to potential factors that may have led to more news stories mentioning autistic adults.

Discussion

Overall, the findings indicate more representations of adult autistics since the publication of Stevenson et al. although, in most cases, the increase has been modest. The only domains in which we documented equal representation of child and adult autistic individuals was in television shows/films and news stories. In general, across websites and books of fiction, approximately 80% or more of representations were still of children. In what follows, we begin by discussing general factors that may have played a role in the overall (slight) increase in representations of autistic adults. We then discuss specific potential reasons for the greater increase in representations of autistic adults in films/shows and news stories than in fictional books before exploring directions for future research on this topic.

As suggested in the Introduction, we believe the increase in overall frequency of representations of autistic adults is related to two factors: the neurodiversity movement and the associated rise of self-advocates. Using social media to organize, autistic adults have challenged multiple stereotypes about autism¹³ and, by their very presence in public spaces, challenge its association with children. To take two examples directly related to infantilizing autism, autistic adults have called out the harm of describing and treating autistic adults like babies and discuss the mistaken idea that autistic people are asexual through online venues such as [Tumblr](#), [Medium](#),³⁴ and *The Art of Autism*.³⁵

While there was an overall increase in representations of autistic adults compared to the findings of Stevenson et al., this increase was generally modest. In most instances (Autism Society of America websites, charity websites, fictional books), the majority of representations were still of children. However, there were some signs of progress even in these cases. For example, even though only 20% of the photos of single individuals on websites of the chapters of the Autism Society of America depicted autistic adults, analysis of the text on these same sites

showed that far more of them (greater than 80%) explicitly mentioned autistic adults and linked to resources specifically for adults. These are clear indicators of an awareness of the existence of autistic adults and the importance of their needs; this awareness is likely linked to increased exposure to the voices of autistic adults inside and outside of the Autism Society. As indicated in the Introduction to Study 1, the Society's "About Us" page says they are "proud to be one of the few organizations to have members on the autism spectrum serving as active members of our board directors as well as in other leadership positions throughout the organization."

Despite these signs of progress, only in U.S. news stories and television shows/films was there equivalent representation of adults and children. Why might more adult characters be represented in fictional films and television shows than in fictional books? We cannot know for sure, but it seems likely that the fact that films and television shows are by nature more collaborative and tend to use consultants may make it more likely that their plots and characters would be influenced by autistic adults.³⁶ The television shows *Atypical* and *The Good Doctor* employ non-autistic autism consultants.^{37,38} The first season of *Atypical* was criticized for having just one autistic actor, and in response the creator of the show added more autistic actors to the second season.³⁹ We speculate that individual authors of fiction are, in general, probably less likely than film producers to collaborate or consult with autistic people and therefore may be more likely to be influenced by prevailing stereotypes of autism.⁴⁰

Similarly, autistic journalists may have played a role in increased representations of autistic adults in U.S. news stories, not only through their own writings but perhaps also by influencing the views of their colleagues.^{41,42} Prior studies of both British⁴³ and U.S.² news stories focused on autism demonstrated an infantilizing bias, so it appears there has been a major shift in the decade since those studies were published. Self-advocates have played a role in educating

(non-autistic) journalists about neurodiversity who in turn play a role in educating the general public.¹²

Where do these findings leave us with regard to answering our title question, “Still infantilizing autism?” and where do we go from here? Notice that “infantilizing autism” can have several different meanings in the context of assessing representations of autism. We focused on quantifying and comparing the relative proportions of child and adult representations in various outlets. But adult autistics could still be infantilized even when there are equal numbers of representations of autistic adults and children or even when the majority of representations are of autistic adults because the manner of representation of the adults may still infantilize them. For example, we found that many of the news stories about adult autistics referred to them as the children of non-autistic adults, which situates the adults as children, thereby infantilizing them. News articles generally contain very few quotes of autistic people and researchers, clinicians, and parents tend to be presented as the experts on autism.¹² These findings indicate the continued privileging of non-autistic people’s perspectives as authoritative in representing autism despite growing recognition that autistic adults are the experts on the experiences associated with being autistic.⁴⁴ This is particularly striking in the context of representing autism in news stories, television programs, films, and books, as expertise concerning what it is like to be autistic is crucial to telling stories that aim to capture autistic experience.

Limitations

We aimed to follow exactly the methods of Stevenson et al., but in some cases were not able to do so because some of the websites Stevenson et al. coded no longer exist (e.g., Fancast and several of the autism charities). Another limitation involves potential ethical implications of the way we coded photos of adolescents in Study 1. Recall that to avoid biasing the data in favor

of the hypothesis (that more representations would be of adults now than in Stevenson et al.), we coded these instances as photos of children. A potential byproduct of this methodological choice is that autistic people who are older might have been misclassified as younger, which could indirectly contribute to the mis-aging of autistic people in ways that infantilize them. A related unintended effect is the harm our results may cause autistic people to learn of their continued marginalization and infantilization.⁴⁵ We acknowledge this possibility but also hope that our findings might spur more attention to the needs of autistic adults⁴⁶ and will encourage research examining other aspects of representations of autism such as the gender and race/ethnicity of those represented.

Conclusions

In most of the sources we studied, there are more representations of autistic adults now than there were when the same sources were coded by Stevenson et al. Multiple factors have likely contributed to this increase. They include autistic self-advocacy, autistic journalists (who not only write about autism but presumably influence their colleagues as well), non-autistic journalists who interview autistic self-advocates as sources, autistic adults serving on boards of autism organizations, the use of autism consultants for television shows, etc. We cannot disentangle these factors, and we think it likely that they mutually influence one another, but we believe that autistic self-advocates have likely played the most substantial role as their very presence in the public sphere exposes non-autistic people who create representations of autism to autistic adults.

Finally, we have seen that the number of representations of adult autistics can improve without the manner of representation improving. While there has been a modest move in the direction of increased representation of adult autistics, some of the ways adult autistics are

represented in these venues suggest that they continue to be infantilized in key respects. Future studies will need to investigate in more detail the variety of ways in which autistic adults are represented, the direct and indirect effects of media portrayals of autistic people (on both autistic and non-autistic people), and ways to improve future representations.

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Authors' contributions

NA did the bulk of the coding, analyses, and writing; JD coded the data for Study 3; JF coded the data for Studies 3 and 4; JD and JF contributed to the interpretation of the data and the writing.

All authors reviewed and approved this article prior to submission. (NOTE: JF was the first author of Stevenson et al. (2011). She was asked to join the project after it had begun to ensure consistency with the methods of data extraction and coding used in the original study.)

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Table 1

Portrayals of Autism on the Homepages of Chapters of the Autism Society of America (those that contained at least one photograph of a single individual)

<u>Chapter</u>	<u>Website</u>	<u>Child Photos</u>	<u>Adult Photos</u>	<u>% Child Photos</u>
Alabama	http://www.autism-alabama.org	1	0	100
Arizona: Southern Arizona	https://as-az.org	3	0	100
California: SF Bay Area	https://www.sfautismsociety.org	2	0	100
California: Ventura County	http://www.autismventura.org	1	0	100
California: Los Angeles	http://www.autismla.org/1/	2	1	67
California: Kern	https://kernautism.org	3	0	100
California: California	http://www.autismsocietyca.org	6	1	86
California: San Diego	https://www.autismsocietysandiego.org/	10	1	91
California: Inland Empire	https://www.ieautism.org	1	0	100
Florida	http://www.autismfl.com	11	1	92
Georgia	https://autismsocietyga.org/	1	0	100
Hawaii	https://autismsocietyofhawaii.org	0	1	0
Idaho: Treasure Valley	http://www.asatvc.org	1	0	100
Indiana	http://www.autismsocietyofindiana.org	2	0	100
Kansas: The Heartland	http://www.asaheartland.org	3	0	100
Kentucky: Kentuckiana	http://www.ask-lou.org	2	0	100
Kentucky: Bluegrass	https://www.asbg.org	3	0	100
Louisiana: Acadiana	https://acadianautism.com	9	1	90
Louisiana: Greater New Orleans	http://www.asgno.org	4	0	100
Louisiana: Greater Baton Rouge	https://www.autismsocietygbr.org	3	0	100
Maine	https://www.asmonline.org	4	0	100
Maryland: Baltimore-Chesapeake	https://www.baltimoreautismsociety.org	1	0	100
Maryland: Howard County	http://www.howard-autism.org	1	3	25

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Michigan	https://www.autism-mi.org	0	1	0
Minnesota	https://www.ausm.org	1	0	100
Nebraska	http://autismnebraska.org	1	0	100
New Jersey: Southwest New Jersey	http://www.solvingthepuzzle.com	1	0	100
New York: Greater Capital Region	https://asgcr.org/	3	0	100
New York: Nassau/Suffolk	http://www.nsasa.org	1	0	100
New York: Western New York	https://autismwny.org	1	0	100
North Carolina	https://www.autismsociety-nc.org	2	3	40
Ohio: Greater Cleveland	http://www.asgc.org	6	1	86
Ohio: Greater Cincinnati	http://www.autismcincy.org	1	0	100
Ohio: Greater Akron	http://autismakron.org	0	1	0
Ohio: Mahoning Valley	https://www.autismmv.org	1	0	100
Pennsylvania: Pittsburgh, INC.	https://www.autismsocietypgh.org	8	4	67
Pennsylvania: Berks County	http://www.autismsocietyofberkscounty.org	1	0	100
Pennsylvania: Greater Philadelphia	http://www.asaphilly.org	1	3	25
Pennsylvania: Greater Harrisburg Area	http://www.autismharrisburg.com	2	0	100
Pennsylvania: Lehigh Valley	https://www.asalehighvalley.org	1	0	100
Pennsylvania: Northwestern Pennsylvania	http://www.autismnwpa.org	1	0	100
South Carolina	https://scautism.org	1	0	100
Texas	http://www.texasautismsociety.org	1	1	50
Virginia: Tidewater	http://www.tidewaterasa.org	2	0	100
Virginia: Northern Virginia:	https://www.asnv.org	0	1	0
Virginia: Central Virginia	https://ascv.org	1	0	100
Washington	http://autismsocietyofwa.org/v2/	1	2	33
Wisconsin: Southern	https://www.assev.org	3	2	60

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Wisconsin				
Wisconsin: Greater Wisconsin	https://www.asw4autism.org	4	1	80

Table 2
Portrayals of Autism on the Homepages of Charitable Organizations Included in Stevenson et al.

Organization	Website	Child Photos	Adult Photos	% Child Photos	Discourse (2009)	Discourse (2019)
Autism Speaks, Inc.	https://www.autismspeaks.org/	5	3	62.5	Child	Child & Adult
Doug Flutie Jr. Foundation for Autism, Inc.	http://www.flutiefoundation.org/	1	0	100	Child & Adult	Child & Adult
Organization for Autism Research, Inc.	https://researchautism.org/	0	0	n/a	Child & Adult	Child & Adult
Autism Society of America Foundation, Inc.	https://www.autism-society.org/	2	0	100	Child & Adult	Child & Adult
Young Autism Program Charitable Foundation, Inc.	http://www.yapcf.com/	1	0	100	Child	Child
Autism International Association, Inc. (now AutismOne)	http://www.autismone.org/	1	0	100	Child	Child
Friends of Autism	http://www.friendsofautism.org/	0	0	n/a	Child	Child
National Foundation for Autism Research	https://www.nfar.org/	1	1	50	Child	Child & Adult

