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Dispatch

Stim, Like, and Subscribe: Autistic Children and Family YouTube Channels

KENNEDY LABORDE RYAN
Carleton University, Canada

The title of this dispatch comes from a play on words of the ubiquitous YouTuber call-out, typically uttered within the first 30 seconds of a video after a cheery "Hey guys!." "Likes" or "thumbs up" bump up the position of a video in the site's algorithm and allow YouTube to fine-tune recommendations by showing users videos that others who have similar interests spend their time watching (Arthurs et al., 2018). This dispatch examines the challenges posed by the family vlogging channel *Fathering Autism (*FatheringAutism*,* n.d.), which focuses on disability and family dynamics and bills itself as a distinctive voice in the digital disability space. I aim to question the oft-muddied distinction between education and entertainment in *Fathering Autism*'s content, in order to contribute to discussions surrounding social justice and Autism. Specifically, I question whether it is ethical to create content that relies heavily on the participation of a nonspeaking autistic child. This question is part of a larger debate that considers whether it's ethical to cast *any* children in homegrown content, given the limits to the consent they can give to being filmed.

Asa Maas, the vlogger behind the *Fathering Autism* channel, has credited his family's success on the platform to their overlapping circles of identity. Maas put it succinctly when he accepted an award at a Healthcare Disruptors Industry conference in November of 2019: not only is *Fathering Autism* a family vlogging channel, it is also an Autism family channel, as well as one that focuses on an autistic girl. A recent systematic review and meta-analysis pegged the ratio of Autism in boys and girls at 3:1, which is higher than the research community's previously stated and widely circulated benchmark of 4:1 (Loomes et al., 2017). This means that families like the Maas' are underrepresented in depictions of Autism, which are only slowly becoming

Correspondence Address: Kennedy Laborde Ryan, School of Journalism & Communication, Carleton University, Ottawa, ON, K1S 5B6; email: kennedylryan@cmail.carleton.ca

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more inclusive of girls and women on the spectrum (Thorpe, 2017). The channel, which has been hosting videos since 2011, focuses on various Maas family activities. Most of their vlogs, which are posted daily, feature Jacksonville-based Asa and his wife Priscilla as well as their two children: 17-year-old Isaiah and Abbie who is 14, nonspeaking, and autistic. The content of the vlogs runs the gamut from coffee runs, pranks, and drone footage to sensory meltdowns and frank discussions about Autism itself. The volume of footage that emerges from the family's lives is astonishing – each video seems to run at an average of 12 to 20 minutes.

According to SocialBlade, a social media aggregator and analytics platform that draws from YouTube's publicly available Application Programming Interface (API),[1] as of December 2019, *Fathering Autism* had 447,000 subscribers, 1,044 uploaded videos, and 86.5 million unique video views. SocialBlade estimates the income the Maas family draws from the channel at somewhere between $2,400 and $38,300 per month, or $28,700 to $459,700 per year (Social Blade Stats, n.d.). These numbers do not include all of the family's income streams from the channel: in addition to revenue generated directly from YouTube, the Maas's also sell their own line of merchandise and consult for companies who wish to better serve the needs of their customers with Autism. They also have quite a robust presence on Amazon Affiliates, an initiative of the Seattle-based company that allows influencers to earn commissions on a curated selection of their favourite products.[2]

An uncomfortable aspect of family vlogs is that performing authenticity becomes the family business; *Fathering Autism* is the main source of the Maas's income as discussed by Asa (FatheringAutism*, 2018)*. Both parents work fulltime as content creators, with Asa producing, editing, and recording daily videos, while Priscilla posts cooking tutorials on her *Pots, Pans, Priscilla* channel. Unfortunately, *Fathering Autism's* success is predicated on a representation of Autism that shows neurodiversity through a neurotypical lens in which the perspective of the autistic subject is wholly absent from the final product. All of Abbie's communication, her signing and stims, are interpreted through another family member, and a significant portion of the videos serve as educational content about Autism (sample titles include "Autistic Bedtime Routine," and "How A Girl With Autism Talks") without any input from Abbie beyond her presence. Abbie has yet to communicate for herself to the camera, and by extension to the audience, which raises the question of how much leeway has been given to that possibility.

What worries me is that the "educational" messages being disseminated come from a neurotypical viewpoint that relies heavily on the medical model to frame Autism as a "condition" that must be "managed." Autism was

[1] An API is what developers use to build apps that mesh with the YouTube platform.
[2] A selection from the *Fathering Autism* affiliates page includes filming equipment favourites, sensory playthings, and road trip essentials.

identified as early as 1911 as a "mode of thinking" rather than a "disorder in and of itself" (McGuire, 2016). This understanding of Autism is analogous with ways of thinking that would later give rise to a social model of disability – one that is only shown in glimpses on the *Fathering Autism* channel. Surveillance of Autism is as old as the naming of Autism itself. Indeed pathologization and surveillance of neurodiverse individuals go hand in hand, an uncomfortable reality that is compounded by the filming and packaging of voyeuristic content that relies on the shock value of "deviant" autistic traits for entertainment purposes. The surveillance of Abbie in the Maas's home is near-constant.[3] It is unclear whether Abbie has given consent to be filmed; it seems that her brother Isaiah has, as he participates actively in the videos. Abbie is non-speaking and communicates differently than the rest of her family, which means that on the *Fathering Autism* vlog they are the sole interpreters of her will and intent. All of her utterances are filtered through one of her family members, either through signing or a communication app on her iPad; this leaves a lot to be desired in terms of self-representation.

When YouTube is the family business, the question of what protections are in place for children whose home has been turned into a workplace emerges. In the case of *Fathering Autism*, the family has been transmogrified into a production team. Each member of the Maas family works to move forward the entertainment product that their life has become. Household tasks that would have previously been routine are now the raw material of their videos. This embellishment of the benign – the performance of authenticity for views – merits further critical scrutiny, especially when it is purportedly done in the name of Autism education. Abbie and Isaiah are examples of a much larger pool of invisible workers: the children of influencers who are labouring in what I've identified through researching this dispatch as a legal and regulatory blind spot. Being children of media influencers puts them in a legal grey area. Conventionally, child stars are labelled as performers and enjoy protections as workers. The California Child Actor's Bill, known colloquially as the Coogan Act,[4] is designed to protect child performers' rights as workers, and contains specific guidelines about the amount of earnings that must be set aside until adulthood, as well as strictly enforceable rules about how many hours a child can spend on set per day. No such protections currently exist for the children of influencers, or even influencer children. The recent decision by YouTube to demonetize content aimed at children seems to be a step in the wrong direction, due to the massive waves of backlash that are currently rippling through professional influencer circles, as well as the ongoing lack of workplace protections for children whose lives

[3] Despite my critique I have no reason to suspect any malicious intentions behind Asa Maas's vlogging. I believe that like most parents he is acting in good faith and attempting to do the best by his children.

[4] The Coogan Act was passed in 1939 in response to the case of Jackie Coogan, a child actor who earned millions only to discover that his parents had squandered the money by the time he turned 18.

are being filmed and photographed for audiences of millions. These children are themselves labourers and the work of producing content is work. These shifting norms are of course a reflection of wider patterns of precarity – ones that tear down traditional workplaces and contracts in favour of zero-hour contracts and "disruption." This casualization leaves children vulnerable to the whims of the same algorithms their parents depend on to make money. Questions are being raised by the platform and people who use it about the ethics of marketing to kids by kids, but what about the question of how to protect kids who are being used as tools of marketing?

If the logical conclusion of inclusion is full participation in public life (ASAN, n.d.), then we must examine how the desire to include people with disabilities plays out in the digital public sphere. Capturing family life on camera invites a level of surveillance into the home as thousands, sometimes millions, of people are made privy to the lives of children as they grow up in front of a lens. Autism family vlogs like the Maas' present us with a difficult question: what are the implications of being someone's caregiver and also their producer?

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