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Keywords

advocacy,
neurodiversity,
self-representation,
YouTube

COMMENTARY: **Challenging Representations of Autism – Exploring Possibilities for Broadcasting the Self on YouTube**

Abstract

YouTube offers potential for many to broadcast their own ideas and concepts to a broad international audience. The take up of YouTube by people with autism as a space for advocacy and awareness raising is discussed in this paper, and the benefits of the environment for enabling people with autism to portray autism in positive and enabling ways are considered. The distinction between knowledge of autism produced within a scientific, medicalised deficit framework as opposed to an experiential knowledge of those with autism themselves is as evident in online spaces such as YouTube as it is in face to face environments, and the wider potential impacts of online spaces on face to face environments will be considered.

YouTube: Possibilities for Self-Presentation

Autism is presented in traditional literature through reference to an individual's "impairments." Much of this literature is dominated by the gaze of the medical model, and has been argued to pathologize the differences within individuals (Kapp, 2011). Wing and Gould's (1979) work identifying a triad of impairments associated with autism has been dominant in shaping understandings of autism. Such a triad focuses attention on "impairments" in areas of communication, socialisation and behavioural flexibility. With the imminent arrival of the DSM V, we will see a move towards a dyad of impairments rather than a triad, with social communication and social interaction being combined into one category (Matson, Hattier & Williams, 2012). Whether we draw on a model of triad or dyad of impairments, such powerful representations serve to construct the individual with autism as one of impairment and deficit. In this paper we argue that alternative self-representations may be available to individuals with autism, which may serve to challenge the discourse of deficit.

YouTube is recognised as the predominant online video sharing site currently available for users of online social networks (Burgess & Green, 2009; Lange, 2007; Lovink & Niederer, 2008; Rotman & Preece, 2010). According to YouTube's own statistics, there are over 800 million unique users accessing YouTube each month who watch over 4 billion hours of video (YouTube, n.d.).

In addition to being a media repository, YouTube also offers embedded social networking features (Ellison & Boyd, 2007) which include the sharing and linking of videos and comments boxes so that viewers can not only comment on the videos, and of course the comments of others, but also rate the videos. Rotman and Preece (2010) note that the use and engagement with YouTube may be multi-layered. In order to upload videos to the site, users must be registered with a YouTube account. However, in order to view videos that are within the public domain, no registration is necessary. YouTube therefore opens up the possibility for a wide-ranging audience, who do not necessarily have to be part of the same social network as is the case in some other forms of social media such as FaceBook. In a similar way to other social networking sites, registered users create personal profiles or "channels," and these channels will vary depending on the scope of information contained within the channel and also the creators' preferences concerning the amount and detail of personal and related information they wish to share with their viewers. YouTube therefore offers the user possibilities for self-presentation in a far-reaching way, potentially attracting viewers through transcending geographical boundaries, and also potentially "topical boundaries." Such topical boundaries can be crossed while a viewer is watching one particular video; recommendations are subsequently suggested, taking the viewer on a potentially intertwining journey through a web of different content. Self-presentation by individuals may therefore potentially be widespread through such processes, despite the "competition" with the other millions of videos hosted by the site.

In presenting themselves, individuals may create their own channels and engage in video blogs or "vlogs," and it is this visual presentation of the self to others that makes online social networks such as YouTube unique in the crafting of self. Previous research, notably Seymour and Lupton (2004) and Bowker and Tuffin (2002), have explored online possibilities for representation in a pre-YouTube era. Such early research considered the possibilities afforded by internet technologies for the crafting of identities online for people with disabilities. More recent social media such as YouTube provides further self-presentation opportunities, extending the possibilities for self-expression and the construction of identities in a public space.

A new body of research has therefore begun to emerge that seeks to examine self-expression through various media platforms such as YouTube, and researchers such as Mahmod (2011) propose a link between the choice of self-expression by individuals and the understanding of our "selves" and our own individual performances. Drawing on their research on the understandings of "Kurdishness," Mahmod proposes that in addition to the online portrayal of topics and the understandings of these, there is a "nexus" between on and offline understandings. Mahmod suggests that it is only through examining the important relationships between on and offline understandings and how these interconnect, will a full exploration of meanings be possible. Such questioning echo's the earlier work of Seymour and Lupton (2004), who postulated whether online environments could serve to enable people with disabilities to transcend the limitations of their offline bodies. The relationship between the on- and offline world therefore needs to be central in such debates, as does the role of powerful structures in our society and their role in shaping the inclusion or marginalisation of individuals (cf. Rappaport, 1981).

In considering the possibilities for self-representation afforded by Internet technologies generally and social media specifically, we argue that the Internet and related technologies potentially provide a crucial tool in the living and sharing of experiences and understandings that would not have been possible previously. In this paper we seek to question whether similar parallels can be drawn for people with autism.

Self-Representations by People with Autism on YouTube

One of the key aspects about the use of YouTube by people with autism is that while there are many contributions in a variety of genres about autism created by neurotypicals (individuals not affected with autism), YouTube

also offers the possibility for many different kinds of people, not just those who are seen to be neurotypical or "normal," to self-present in a dynamic and engaging way, potentially reaching millions of viewers in a way that existing media would find difficult or impossible. The video blogs that can be created and broadcast on YouTube do not have a gatekeeper assessing the suitability and digestibility of the presentation, nor do they require specific skills in academic or recreational writing styles. Video blogs can be created by individuals without necessarily the need for specialist equipment, and distributed within a host site that attracts millions of viewers. Indeed, the visual nature of such broadcasts is one of the elements that may make YouTube unique in the self-presentation possibilities for individuals, including those who identify as autistic. There has been much research previously that has examined the representations of autism within textual communities (see, for example, Bertilsdotter Rosqvist et al., 2012; Brownlow, 2010; Brownlow & O´Dell, 2006). However, Rotman and Preece (2010) argue that a key characteristic of the YouTube online community is that of face-to-face mediated interaction, and it is this visual self-presentation and visual viewing of others that is key in differentiating this media from more textual online communities.

While several researchers have argued that people with autism may be able to capitalise on textual means of communicating (see, for example, Davidson, 2007, 2008), the fact that YouTube enables self-broadcasting in a visual form opens up a range of new possibilities. We have previously argued (see, for example, Bertilsdotter Rosqvist et al., 2012; Brownlow, 2010) that online discussions may be a useful tool for people with autism in that they can facilitate communication through a medium that does not require face-to-face interaction and all of the social nuances that remain an integral part of this. YouTube may offer further possibilities in that the viewer is engaged with a visual representation of an individual, but the broadcast can be created in isolation from social expectations.

Indeed, this form of visual media is one that has been embraced by some members of the autistic community. In addition to the many documentaries and presentations of autism created by others, an initial search by the present authors in YouTube with the terms "autism advocacy" returned 1,160 possibilities, when conducted in February 2013. The increased upload of all videos to YouTube daily would suggest that this figure will continue to increase. While users posting material can create their own key words and tags, and therefore not all of the material is created by people with autism, it is clear that several examples of "autistic-owned" channels are harnessing this technology as an avenue for self-presentation. Examples of such channels include Autism Self-Advocacy Network and the Wrong Planet (see More Resources).

Researchers such as Shifman (2011) have also argued that YouTube is not merely a platform for broadcasting content. Users are therefore not necessarily utilising the technology merely to broadcast themselves. Shifman suggests that there is a growing body of research that seeks to examine the view of YouTube as a social network and one that plays a key role in the development and crafting of communities. YouTube may therefore offer people with autism not just a means of broadcasting themselves by themselves, but also an opportunity for the development of a community of like-minded individuals, developing content and shaping ideas initially through the comment functions, and potentially further linking through other technologies that utilise real-time methods.

Possibilities for Shaping New Understandings of Autism?

With the flexibility afforded through YouTube in terms of the content and the production of self-broadcasts, the question arises concerning whether this technology also offers the possibilities for shaping new understandings of autism, ones that are very much generated from the individuals who identify themselves with the label. YouTube may be important as the video blogs. It could be a way of offering alternative ways of thinking about autism. Seeing the individuals with autism present their own self potentially poses challenges to some of the previously held ideas concerning the "impairments" of people with autism, and the competencies of such a group. "Impairments" therefore with respect to communication may

be challenged by providing an alternative space in which to express ideas and commentaries on key issues such as friendship, intimate relationships and employment. Exchanges facilitated by YouTube could therefore be considered a way of communicating ideas without having to engage in the social nuances and practices that are part of face-to-face communication in a social space dominated by neurotypical understandings. New social media such as YouTube may therefore be instrumental in providing a platform whereby people with autism can present themselves and potentially access a far-reaching audience in a way that was not possible before.

Indeed, channels on YouTube that feature people with autism offer a portrayal of individuals who can communicate effectively and reflect on a variety of issues – tasks that we would be led to believe by professional and academic literature are challenging or not possible due to their inherent "impairments in communication" and lack of "theory of mind." A key example of this is the channel created by Aspie37 (see Garry Burge, n.d., in More Resources).[1] Over numerous video blogs, the creator of Aspie37 discusses and reflects on a range of issues pertinent to autism spectrum disorder, including the use of the new DSM-V in considerations of mild autism, reflections on the Asperger label and "why being Aspie needs to be seen as cool." The self-identified purpose for the channel is one of raising awareness of Asperger syndrome in adults, and in doing so the creator draws heavily on the narratives of Aspergers as a "different wiring" of the brain – a difference and not a deficit.

However, as well as the possibilities in terms of crafting alternative representations, Chou, Hunt, Folkers, and Auguston (2011) caution against the representation of ideas on YouTube, particularly the privileging of certain narratives over others. It may therefore not be quite as straightforward as an individual creating a broadcast, and this broadcast being considered "equal" among other representations of a similar topic, such as autism. Müller (2009), among others, claims that traditional and elit-ist conceptions of authorship continue to work

as a sort of conservative power among users of YouTube (Jones & Schieffelin, 2009; Müller, 2009). All video blogs on YouTube may therefore not necessarily be considered equal, and the traditional power relationships concerning "expert status" continue to operate within this medium. In contrasting positions, YouTube can be seen as both a platform for open exchange, peer support and creativity, and also as a disciplinary space of symbolic violence (Bourdieu, 1991) or of deception and disruption (Donath, 1999).

The question of several representations of autism being broadcast simultaneously on YouTube, some by self-identified autistic advocates, and some by professionals drawing on the medical model, raises questions concerning which representations of autism result in being "taken-up" by the audience. The distinctions therefore between professional knowledge and experiential knowledge offered by people with autism themselves is as evident in virtual spaces such as YouTube as it is in more traditional contexts (see, for example, Bertilsdotter Rosqvist, 2012).

A further consideration is the importance of the comment function in YouTube (Siersdorfer, Chelaru, Nejdl, & San Pedro, 2010). The comment function provides the viewer an opportunity to comment on the video, and therefore interact with its creator. With respect to the self-presentations of people with autism on YouTube, these may be important, as we can therefore see not only a potentially alternative broadcasting of the self, but also a commentary of the take up of these representations by others.

The final note of caution when considering the potential role that YouTube may play in alternative representations of autism concerns the way that individuals use the Internet and related technologies. Kidd (2011) notes that the majority of individuals in the general public don't necessarily use the web for finding out new information, but rather as a way of consolidating what they already know. So in terms of self-broadcasts about autism, we need to be mindful that viewers of the videos may already be like-minded individuals, who in a sense are seeking to confirm their own views and look for other like-minded individuals.

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1   Permission has been granted from the owner of this channel to cite their work in this paper

While there is therefore the potential for a video to be viewed by millions of individuals and potentially challenging individually held views about people with autism, there is still the question remaining concerning whether such videos will be primarily sought out and watched by individuals who already think in more "neurodiverse" ways.

Kidd (2011, p. 106) therefore argues that we should be cautious in discussing the empowering nature of such technologies:

> To assert that a public is empowered is to assume not only that they have access to means of making and distributing media, but that they are actively engaged in that empowerment (not just using those avenues opened up to them).

Following on from Kidd's ideas, we therefore need to be cautious in an assumption that just because a more divergent range of autistic voices and representations can be seen and heard on YouTube, this does not necessarily mean that such alternative representations will be mirrored in wider face-to-face society. In order for this to happen, wider held ideological beliefs would need to be challenged and shifted, and this would require representations such as those on YouTube to spill over into "on the ground advocacy." With respect to autism, this is a trend that is growing, with advocates affected by autism regularly giving keynote addresses as autism conferences, and it may be that these, in collaboration with online social networking and representations such as those on YouTube, can portray alternative ways of thinking about autism and the possibilities for our understandings.

Key Messages From This Article

People with disabilities: YouTube may provide an avenue through which you can express yourself in the way you want to be seen and not how other people want to portray you.

Professionals: New technologies may provide a range of different ways for people with autism to express themselves, sometimes in a sophisticated manner, which may challenge some professional understandings about them and their abilities. Autism can be presented as a *difference* rather than a *deficit*. Such alternative representations of people with autism has implications concerning the way that professionals work with people with autism, raising the need to re-negotiate the assumptions about and roles afforded to people with autism in professional practice and surrounding policy. Such representations also impact on research practices, highlighting the need to focus on the position of autism as a *difference*, rather than research focusing on the "impairments" associated with autism.

More Resources

The following links are example YouTube channels focusing on broadcasting the self:

Autistic Self Advocacy Network. (n.d.). Retrieved from http://www.youtube.com/user/autselfadvocacyntwk

Garry Burge. (n.d.). Retrieved from http://www.youtube.com/user/aspie37

The Wrong Planet. (n.d.). Retrieved from http://www.youtube.com/thewrongplanet

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