



Contents lists available at ScienceDirect

Research in Autism Spectrum Disorders

journal homepage: www.elsevier.com/locate/rasd

Support, socialise and advocate: An exploration of the stated purposes of Facebook autism groups

Susan Abel*, Tanya Machin, Charlotte Brownlow

School of Psychology and Counselling, University of Southern Queensland, West St, Darling Heights, Queensland, 4350, Australia



ARTICLE INFO

Keywords:

Autism
ASD
Social support
Facebook groups

ABSTRACT

With a rapidly growing global population of just over two billion users, Facebook has changed the way many people engage with each other. Whilst the autism community—autistic people, their families and carers, and their broader support network—are represented in this population there is limited research about how or why this community intends to use Facebook to connect and communicate. This exploratory study aimed to characterise the stated purposes of Facebook groups related to autism and their target membership. The terms autism, Asperger, ASD, Aspie, and wrong planet were used to search for Facebook groups. Using a content analysis, the group name, description, privacy status and member count of 500 autism groups on Facebook were examined. The groups had a combined membership of 905,655 English-speaking users and were created for support (60.4%), social companionship (16.4%), advocacy (15.8%), treatments (5.6%), sales (1.0%) and fundraising (0.8%). Most of the groups had a target membership of parents and families (57.4%), autistic people (23.4%), and women (10.4%). Many groups specified group etiquette (36.4%), or the geographic location of members (42.8%). Of the groups targeting autistic people, 77.8% used identity-first language, while 58.2% of groups targeting parents and families used person-first language. Separate and shared neuro-spaces appear to be negotiated within these Facebook groups and this could stimulate critical discussion around the autism community's engagement with social media. These Facebook groups are designed to provide support to autistic people and their families and to provide social networking opportunities for autistic people.

1. Introduction

For many people in the world today, the internet is an integral part of their everyday lives and has transformed the way they communicate with others. There is an almost seamless flow between the online and offline lives of the 2.8 billion people who use social media globally (Kemp, 2017). This is particularly evident in social media platforms like Facebook, which has 2.01 billion users worldwide (Facebook, 2017a). In the United States, 79% of all online adults now use Facebook (Greenwood, Perrin, & Duggan, 2016), and in Australia, 70% of the population are Facebook users (Cowling, 2017).

Facebook's focus is on facilitating the growth of online communities through their Facebook *groups* function—with more than a billion Facebook users currently members of groups (Facebook, 2017b; Novak & Spilleer, 2017). Facebook groups are characterised by a key shared interest, for example an interest in autism. Facebook (2017a) reports that for some users these meaningful Facebook groups are not only an important part of their online experience, but a fundamental part of their real-world support structure. Some

* Corresponding author.

E-mail addresses: Susan.Abel@usq.edu.au (S. Abel), Tanya.Machin@usq.edu.au (T. Machin), Charlotte.Brownlow@usq.edu.au (C. Brownlow).

<https://doi.org/10.1016/j.rasd.2019.01.009>

Received 8 May 2018; Received in revised form 24 January 2019; Accepted 27 January 2019

Available online 05 February 2019

1750-9467/ © 2019 Elsevier Ltd. All rights reserved.

members spend most of their time on Facebook engaging with these groups (Facebook, 2017a). One way to explore how Facebook groups could be meeting the needs of individuals is to utilise the theory of uses and gratifications. The uses and gratifications theory is concerned with how people use media (in this case Facebook groups) to satisfy their needs (Whiting & Williams, 2013). Recent studies have found that people use Facebook to meet others, maintain relationships, monitor relationships, and to seek information (Ellison, Steinfield, & Lampe, 2006; Machin, Jeffries, & Machin, 2014). Social media has become an integral part of many people's everyday life so it is a potentially powerful tool for service providers to the autism community. If practitioners know why their client base is using Facebook, they could investigate new ways to use social media to meet client needs (e.g., if there are many autism awareness groups aimed at parents, service providers may investigate ways of providing accurate information for distribution through these groups).

This study seeks to examine Facebook groups related to autism spectrum disorder (ASD). There are a few studies that have established that autism support groups aimed at parents of autistic children exist on Facebook (e.g., Mohd Roffeei, Abdullah, & Basar, 2015; Searing, Graham, & Grainger, 2015), and research establishing that autistic people are using social media for purposes such as support, information seeking, and friendship (e.g., Brownlow, Bertilsdotter Rosqvist, & O'Dell, 2015). However, to date there has been no broader examination of what types of autism Facebook groups exist nor why the autism community, including autistic individuals, parents, and professionals, might use them. It is acknowledged that the terminology used to describe such stakeholders can present challenges (see discussions by Davidson, 2008). Although not universally preferred by autistic people, disability-first language will be used in this paper to indicate that a majority of autistic adults show a preference for the use of disability-first language (Kenny et al., 2016), and that they feel its use recognises and validates their autistic identity (Autistic Hoya, 2011).

Support groups play a vital role in helping people manage the challenges associated with autism by providing a network of social and emotional support, as well as trusted information (Chuang & Yang, 2010). The first parent-oriented online autism support group was established in 1991, with the aim of providing emotional support and information about autism (Dekker, 2000). Various studies have found that parents use online forums in five key ways to: (a) make sense of autism; (b) search for meaning; (c) seek support for adjusting to changes; (d) provide mutual support and encouragement; and (e) create opportunities for a narrative sharing of experiences (Huws, Jones, & Ingledew, 2001; Reinke & Solheim, 2015).

Online social support may also be a good “fit” for autistic people. Research suggests that asynchronous, non-face-to-face characteristics of online communication is well aligned with the processing style of many autistic people (see Bagatell, 2010; Burke, Kraut, & Williams, 2010). Specifically, online communication provides time for autistic people to process and develop responses, as well as reducing self-consciousness about paralinguistic cues. However, whilst autistic individuals and their parents are each stakeholders in the autism community, historically, autistic people have found that joining parent support groups is not always helpful (Sinclair, 2005). For example, the parental focus on a search for a cure can be offensive to autistic adults who report feeling objectified when the only interest from parents is related to finding some understanding about their own child (Dekker, 2000). Autistic people may therefore be motivated to seek *neuro-separate* spaces where they don't have to conform to neurotypical norms (Sinclair, 2005). To this end, autistic online spaces such as Autism Network International's pen-pal list (Chamak, 2008), Dekker's (2000) “Independent Living on the Autistic Spectrum” e-mail list, and autistic advocate Kathleen Seidel's blog and website, “Neurodiversity” (Offit, 2008) were set up to allow members to seek and provide social, emotional, and practical support, as well as advocate for improved support services (Sinclair, 2005). Autistic people may also be motivated to use online groups for opportunities to share their experiences, query the negative portrayal of autism by neurotypicals, and posit a different-but-equal autistic identity (Bertilsdotter Rosqvist, Brownlow, & O'Dell, 2013; Sinclair, 2005).

While there is a history of previous research examining the use of online support more broadly for autistic individuals and their families, there remains a paucity in research that specifically focuses on the role of Facebook. One notable exception to this is the work of Mohd Roffeei et al. (2015), who found that support was a central function in the Facebook parent groups in their study, with a clear role for both informational and emotional support, as well as individual esteem support for members. The relative lack of empirical research examining the use of Facebook by this community is in contrast to the reported use of Facebook by individuals, and the number of Facebook groups that exist which draw on a membership of parents of a child with autism. The present research seeks to go some way to address this gap in knowledge and explore the group descriptions of communities who specifically focus on parents of children with autism.

1.1. Aims and research questions

It is not possible to ascertain how members are using Facebook groups without joining them, however it is possible to explore members' *intended* use of the groups. Group creators provide information about the purpose, or intended use of the group via the group name and description (e.g., support group). Facebook users join the group based on their interest in the group's stated purpose. Thus, the number of members in any category of group purpose may indicate the relative level of interest from the target audience in participating in a group with those stated purposes. The overall aim of this research was to discover and describe why, or to what purposes, the autism community intends to use Facebook groups. Thus, the first research question proposed is: *What are the stated purposes of English-language Facebook groups related to autism?*

Given that stakeholders in the autism community may use Facebook groups in different ways, it is also important to consider target membership of particular groups. Therefore, it is possible that intended group purposes will vary according to the target stakeholder group. The second research question aims to discover and describe the different autism community stakeholders using Facebook groups: *What is the target membership for Facebook autism groups?*

The group creator sets group privacy settings, and have three options. A setting of “public”, means that anyone can see the group,

its members and their posts. In addition, any Facebook user can join the group (no administrator permission is required). A group privacy setting of “closed” means that whilst anyone can see the group and its members, approval (either by an administrator or another member) is required to join: the content on the group wall is only visible to members. Groups which are set as “secret” are excluded from this study as they may be joined by invitation only, and no evidence of the group is visible to non-members (Facebook, 2017c). The group creator’s use of the group name and description fields provides important information about group characteristics to potential members. Characteristics including geographic location of members, group etiquette, target membership, and even the language used to describe autism may influence a prospective member to join. The autism community prefers to talk about autism in varied ways (Kenny et al., 2016) and this may be demonstrated in the group self-presentation information according to the target membership. This leads to the third research question: *What group characteristics are present?*

2. Method

2.1. Research design and procedure

2.1.1. Content analysis

To investigate the research questions, a content analysis of the descriptions of 500 English-language Facebook groups related to autism was conducted (see Krippendorff, 2004; Neuendorf, 2017). Analysis of the data allowed inferences to be made about the author, the intended audience, and the meaning in the text (Zhao, 2014). This process involved (a) the creation of a codebook, which specified the classification rules, (b) the use of the codebook to gather information, and (c) drawing of inferences about the data.

2.1.2. Ethical considerations

Whilst information which is publicly available on Facebook can be a comprehensive digital archive of material for researchers, it is considered to be somewhere in between archival data and private human interaction (Zhao, 2014). Therefore, ethical issues of informed consent and privacy of research subjects still exist, and must be examined (Eysenbach & Till, 2001). An ethical application was therefore applied for and approved by the host university.

2.1.3. Data set selection

The first research question examined the intended purposes of Facebook autism groups. Therefore, the group name and group description (i.e., the stated purpose of the group) were included as units of data analysis. The second research question aimed to discover the target membership for Facebook autism groups. The group name and description also provided information about these categories. The group privacy setting was selected as a unit of data analysis to give a richer description about the stated purposes of the groups (i.e., most of the support groups might be closed if members are discussing personal information). To explore demographic information about the target membership, information in the *group members* field was included.

A further consideration for data set selection is the language of the group. Facebook is a global phenomenon however sampling was restricted to Facebook groups that were related to autism, and operated in English. It was assumed that creators of groups related to autism would use words in their group name or description which indicated that autism was of interest of the group. It was also assumed that these autism-related words would vary according to the creator’s preference for describing autism. Kenny et al. (2016) found that the terms “autism”, “ASD”, “Asperger”, and “Aspie” were favoured by various stakeholder groups in the United Kingdom autism community to describe autism, therefore these terms were selected to identify the Facebook groups that would be relevant for this study. The final search term was “wrong planet”. The website Wrong Planet was established in 2004 as an online autistic social community. It continues to offer discussion boards about a wide variety of topics and has well over 2 million posts (Jordan, 2010). Wrong planet was selected as a key search term because it has become commonly used slang to describe how autistic people feel about their place in the world (Moran, 2014).

2.1.4. Facebook search strategy

This study employed a data extraction approach known as *data scraping*—also referred to as web harvesting, web scraping, or web content mining (Landers, Brusso, Cavanaugh, & Collum, 2016). To scrape data from a website, a software programmer writes an algorithm which when executed, extracts the desired human readable output from the website and writes the data to a file. In order to check for consistency of data identification, an additional manual search using Facebook’s built-in search engine was completed to provide a rigorous check of the methodology.

On 27th June 2017, a data scrape algorithm was executed to collect the specified units of data using the key words autism, ASD, Asperger, Aspie, and wrong planet. On 2 July 2017, the first author used Facebook’s internal search function using the same key words to compare results.

2.2. Data extraction

Data scraped from Facebook on 27 June 2017 yielded 1453 groups. After screening the group names and descriptions, 1019 groups were removed: 293 groups were not in English, 286 groups were duplicate records, 56 groups were excluded as there was no data in the description which could be coded, and two groups were removed because the group administrators stated that they were inactive. A further 382 groups were removed as they were not related to autism, leaving 434 groups to analyse. For example, whilst it was obvious why the Facebook search algorithm returned the details for a group with an interest in a breed of dog, *Aspie Pug Family*

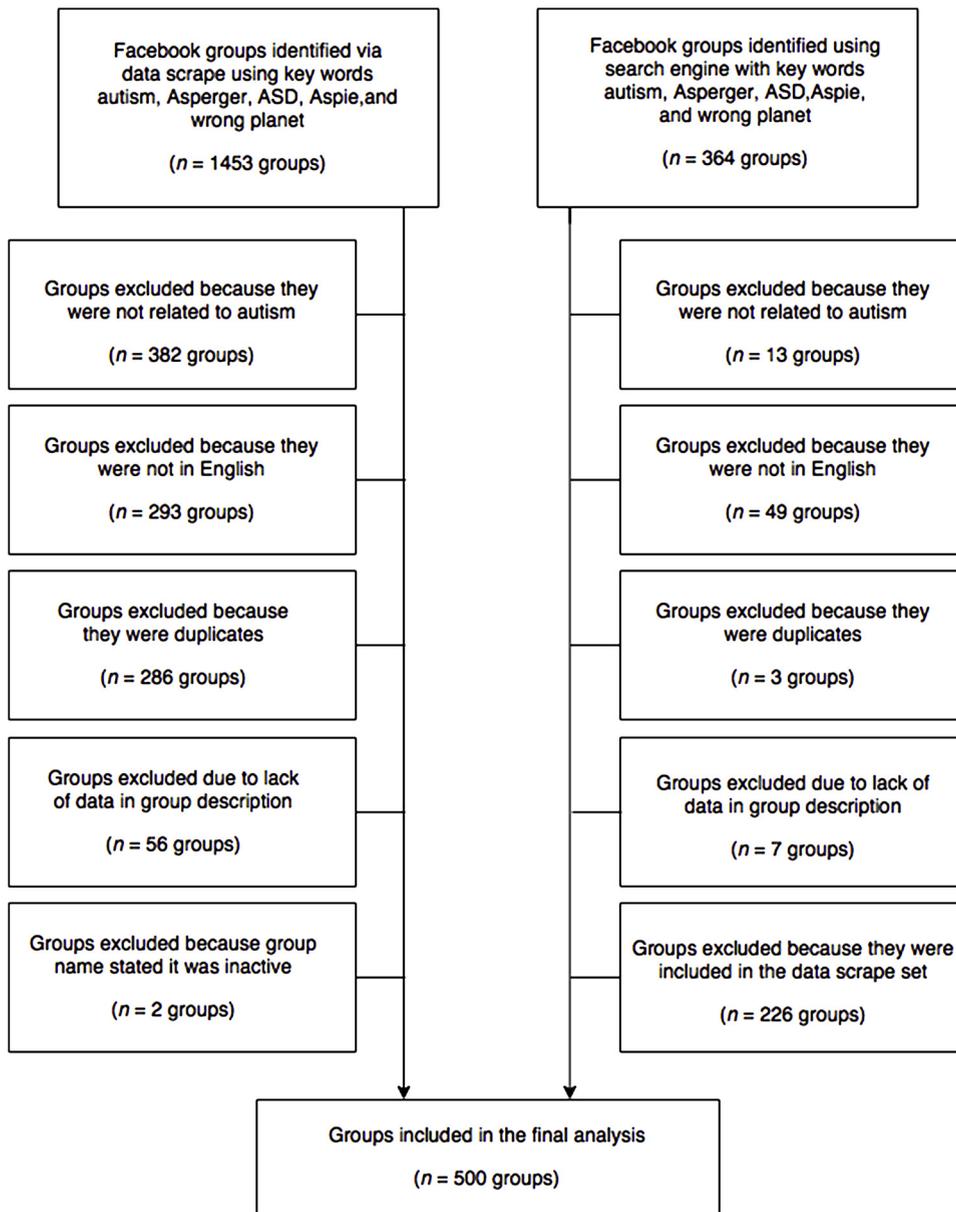


Fig. 1. Flow diagram of group selection process.

(ca. 2017), in other instances, neither the group name nor description included any of the search terms. For example, the [NCDA Executive Director's Corner](#) (ca. 2017) was returned by the search and no text relating to autism was found in the description. The reason for these anomalous results from the Facebook algorithm is unclear and highlights the need for manual checking of returns. The manual Facebook search conducted on the 2 July 2017 initially identified 364 groups. After screening the group names and descriptions in this data set, 13 groups were not related to autism, 49 groups were not in English, three groups were removed as they were duplicate records, seven groups were excluded as there was no data in the description which could be coded, which left 292 groups.

To identify the groups that would be included in the final dataset, the two datasets were combined. Of the remaining 292 valid autism Facebook groups collected by manual search, 226 groups had already been collected via the data scrape technique so they were removed, leaving 66 groups from this data set to analyse (i.e., an extra 66 groups which were not collected by the data scrape method). Fig. 1 shows a visual representation of the extraction process.

2.3. Coding scheme development

A comprehensive coding scheme was developed, covering the four data items collected (i.e., group name, description, members,

and privacy setting). Using this coding scheme, the contents of the resulting 500 Facebook group records were coded by the first author into a Microsoft Excel coding sheet. For this study, three object level categories were chosen, the stated purpose of each group, the target membership for each group, and the characteristics of each group. This informed the researchers about the type of information they were seeking within the raw text. For example, a group that stated in the description that it was a “support group for parents”, was coded to a purpose category of “support” and a membership category of “parents and families”. As this was an exploratory study, attribute level categories were not pre-determined. These categories were identified by the researchers during the pilot coding stage outlined below, resulting in the development of a codebook. The subsequent codebook developed for this project showing object and attribute level categories may be found in Appendix A.

2.3.1. Pilot coding stage

To address issues of reliability, the initial group names were analysed through NVivo to get a broad understanding of the common descriptors of the stated group purpose before a more thorough hand coding process. The next step involved the first and second authors independently coding 55 groups, which were randomly selected from the full dataset and which represented just over 10% of the total number of groups. These codes were consistent with the NVivo categories. This analysis resulted in the identification of six preliminary categories for stated group purpose: support, social, advocacy, treatment, sales, and fundraising. Additional groups were further identified that were removed from the dataset for not meeting the selection criteria. The majority of the coding disagreement focused on whether the groups could be coded as more than one type of group or group purpose. For example, was the group a social group or a support group? Any disagreements were discussed until agreement was reached. Cohen's kappa was calculated with this data, and represented a substantial level of inter-rater agreement ($K = 0.66$).

At times, the coding process was not straightforward as groups did not always fall into mutually exclusive sub-categories, so the codebook specified how decisions were to be made when there were disagreements between coders. If attribute-level categorisation could be made from the group name it was allocated as such. For example the [Autism Support Central Texas \(ca. 2017\)](#) group was coded for a group purpose of support. If there was not enough information in the group name to glean the message about purpose or target membership, information from the group description was utilised. For example, the [QLD Autism Group \(ca. 2017\)](#) group name did not provide enough useful information to determine the purpose of the group. However, a purpose of support and a target membership of parents was gleaned from the associated description: “A group for parents/ carers. Ask for help. Post some news. Support one another or maybe just vent!” ([QLD Autism Group, ca. 2017](#)).

Some records could be coded into two or more categories of purpose. For example, the description for the [Autism Support Central Texas \(ca. 2017\)](#) group indicated a purpose of support, but the word “friendships” in the description: “Creating Support and Friendships for those of us who are parents or caregivers of children with Autism” ([Autism Support Central Texas, ca. 2017](#)) indicated that this group may also have had a social purpose. In records such as this, the first purpose indicated in the group name was allocated or if none could be gleaned, the first purpose indicated in the description was used. The same coding rule was applied to the category for target membership.

3. Results

3.1. RQ1: what are the stated purposes of english-language facebook groups related to autism?

The first research question aimed to discover and describe intended purposes of autism Facebook groups. It also provided information about the combined group size by purpose, to give an indication of the relative interest in that stated purpose. The majority of autism groups on Facebook were support groups (60.4%, 302/500), followed by social groups (16.4%, 82/500), and then advocacy groups (15.8%, 79/500). In total, 5.6% (28/500) of groups were treatment groups, 1.0% (5/500) were sales groups, and 0.8% (4/500) were fundraising groups.

3.1.1. Distribution of members in Facebook autism groups

A total of 905,655 Facebook English-speaking users were identified as members of one or more of the 500 autism groups. The support groups were not only the most frequent groups but also contained the most members (617,809, 68.2%). Advocacy groups were the second most joined groups (135,371, 14.9%), followed by treatment groups (83,447, 9.2%), social groups (61,054, 6.7%), sales groups (5053, 0.6%), and fundraising groups (2,921, 0.3%).

3.2. Overview of group stated purposes

3.2.1. Support groups

For the purposes of this study, support groups were conceptualised to include emotional, or informational support delivered through the group network of friends and acquaintances ([Bender, Jimenez-Marroquin, & Jadad, 2011](#)). This is often described as *social support* in the literature (see [Braithwaite, Waldron, & Finn, 1999](#); [Query & James, 1989](#)). The overarching stated purpose of the Facebook support groups was to facilitate emotional support via member sharing of stories. For example, in one of the support groups for parents and carers, the group description states “This group is a place where all people that are affected by autism can get together to share information, laugh, cry and generally be there to help each other out with support”. Group descriptions frequently mentioned that the groups provided a platform to seek and receive information (112/302, 37.1%) and advice (84/302, 27.8%).

3.2.2. Social groups

Like the support groups, the social groups also encouraged member sharing of stories, but the focus of the social groups was oriented towards enjoyable companionship with other group members to share their common interest. Some of the autistic groups were dedicated to interests such as religion, arts, music, or gaming.

3.2.3. Advocacy groups

The conceptualisation of advocacy in research by Boshoff, Gibbs, Phillips, Wiles, and Porter (2016) has been adopted. The stated purpose of advocacy groups was to promote public understanding about autism, make a service or support available to an individual or group, or promote the welfare of an individual or group. Of the 79 advocacy groups, six groups wanted an anti-vaccine film called *Vaxxed* (Wakefield, 2016) to be made available for public viewing. There were 56 groups dedicated to autism awareness. Their stated purpose was to provide education about autism or to share the group creator’s personal experience. The remaining 17 advocacy groups were set up by non-government organisations to provide instrumental assistance to families and individuals (e.g., financial assistance, connecting them with play groups).

3.2.4. Treatment groups

These 28 groups promoted treatments and “cures” for autism. They also aimed to provide informational support to families undergoing treatments. Of the treatment groups, six were related to behavioural therapies such as speech therapy or applied behavioural analysis. Chemical treatments were promoted by six groups, including the use of medical cannabis and “living oils”. There were 16 groups whose treatment was either not specified or unidentifiable. For example, the “Andy Cutler protocol” (Fight Autism & Win Detoxing Kids, ca. 2017) and IonCleanse by AMD for ASD (ca. 2017) appeared to be branded treatments, but no further information was provided to allow the type of treatment to be identified.

3.2.5. Sales groups

These five groups provided a forum to sell used autism-related items such as books and autism awareness jewellery.

3.2.6. Fundraising groups

These four groups were created to attract financial resources for an autism organisation or unspecified autistic children through an event, product, or service.

3.3. RQ2: what is the target membership for Facebook autism groups?

The second research question recognised that autism community stakeholder groups might be using Facebook autism groups in different ways. The first target membership that was indicated in order of priority, by the group name or group description was used. In some groups, the target membership was clearly defined via the name selected for the group. For example, neurotypical women in a relationship with an Aspie partner. However, some groups indicated their target membership in the group name (e.g., autism parents), but allowed that other stakeholders were also permitted to join the group in the description (e.g., open to autistic adults).

The three most commonly targeted membership categories for autism groups on Facebook were: (a) parents and families of an autistic person (287/500, 57.4%), (b) autistic people (117/500, 23.4%), and (c) women (52/500, 10.4%). Table 1 shows the target membership by stated purpose category of Facebook autism groups. Some target members can be included in more than one category. For example, a group which targeted autistic mothers is included in the count of the groups targeting “autistic people”, “women”, and parents and families”. Neither the sales groups nor fundraising groups specified a target membership.

3.3.1. Target membership for support groups

Through the coding process, it became clear that most of the support groups had distinct target memberships: parents and families (223/302, 73.8%), autistic people (50/302, 16.6%), the romantic partner of an autistic person (13/302, 4.3%), women (46/302,

Table 1
Target Membership of Facebook Autism Groups by Group Stated Purposes.

Target membership	Support		Social		Advocacy		Treatment		Sales		Fundraising	
	n	Members	n	Members	n	Members	n	Members	n	Members	n	Members
Parents and families (n = 287)	223	530,327	20	33,056	27	58,187	17	57,395				
Autistic people (n = 117)	50	65,818	62	27,998	5	19,832						
Partners of autistic people (n = 13)	13	4620										
Women (n = 52)	46	65,306	5	3,584	1	25						
Men (n = 2)	2	1,636										
Professionals (n = 1)					1	117						
Not specified (n = 50)	23	20,020	4	57,235	9	26,052	5	5,023	4	2,921	5	3,574

Note. The target membership of some groups were eligible for inclusion in multiple categories: e.g., a target membership of mothers was included in the categories of women and parents and families.

15.2%), or men (2/302, 0.7%).

3.3.1.1. Support groups for parents and families. These were the most common type of Facebook autism group (223/500, 44.6%). Parent and family support groups were also the most frequently joined groups: 58.6% of all Facebook autism group users were members of one or more of these groups (530,327/905,655).

3.3.1.2. Support groups for autistic people. Of the groups with a target membership of autistic people (50/302, 16.6%), further analysis identified that 12 were aimed at women, and five at autistic parents.

3.3.1.3. Support groups for partners of autistic people. A small number of groups targeted the partners of autistic people (13/302, 4.3%). Whilst the neurotypical or autistic status of the target membership was not specified in many of the relationship support groups, the language used in the descriptions indicates that they were probably support groups for neurotypical partners who face challenges in their relationships with an autistic partner.

3.3.1.4. Support groups for women. Women were specified as the target members in 15.2% of the support groups (46/302): 10 groups were for autistic women, two groups for autistic mothers, 28 groups were for mothers of autistic children, and six groups were for female partners of an autistic person.

3.3.1.5. Support groups for men. The two groups which targeted a male membership were both aimed at fathers of autistic children.

3.3.2. Target membership for social groups

Most of the 82 social groups were created to provide social companionship for autistic people (62/82, 75.6%), followed by social groups for families (20/82, 24.4%).

3.3.2.1. Social groups for autistic people. Whilst the 62 groups which aimed to provide social companionship for autistic people were the second most common type of group overall (62/500, 12.4%), their membership was comparatively small comprising only 3.1% of the total membership (27,998/905,655). Some of the groups for autistic people were based around an interest such as music or gaming, however many of them described being an online space in which members could share their interests with like-minded people.

3.3.2.2. Social groups for families. These 20 groups were quite varied in their intended social purpose with some offering offline social events such as surf camps and gaming meet ups. Others were online spaces for families to meet each other and share amusing stories, or pictures of autism tattoos.

3.3.3. Target membership for advocacy groups

Most of the 79 advocacy groups did not specify a target membership, however 34.2% (27/79) had a target audience of parents and families.

3.3.4. Target membership for treatment groups

Over half of the 28 treatment groups were aimed at families (17/28, 60.7%). Where the group did not mention parents or families, the target membership was coded as not specified, however it is most likely that potential members are also families as the descriptions often talked about treatment in relation to children.

3.4. RQ3: what group characteristics are present?

The third research question explored group characteristics through the group privacy settings and group self-promotion material (group name and description). A privacy setting of ‘closed’ applied to 73% of the groups (365/500). A pattern was identified that 16.0% of the groups (80/500) specified a membership demographic which was enforced by the group administrator through membership screening. In addition, analysis identified that 42.8% of groups (214/500) identified the mandatory or assumed geographical location of members. Group etiquette—which included explicit activity rules about what may (or may not) be discussed or posted within groups—was given in the group descriptions of 36.4% (182/500) of all groups. A marked difference in the words used to describe autistic people was found between groups which targeted autistic people and those that targeted neurotypical people. Of the groups which targeted autistic people, 77.8% (91/117) used identity-first language, while 58.2% of groups (167/287) which targeted parents and families used person-first language. [Table 2](#) shows the number of groups with closed privacy settings, which screened new members via administrator approval, provided assumed or mandatory geographical location of members, or specified etiquette rules.

3.4.1. Privacy settings of support and social groups

Most of the support groups were ‘closed’ (259/302, 85.8%). The social groups were also predominately ‘closed’ (68/82, 82.9%). Of the social groups which targeted autistic people, 90.3% were ‘closed’ (56/62).

Table 2

Group Characteristics Demonstrated Through Privacy Settings, Name, or Description Shown as Number of Groups and Percentage of the Group Type (in Parentheses).

General stated purpose	Privacy setting closed (n = 365)	Membership screening (n = 80)	Geographical location (n = 214)	Etiquette rules (n = 182)
Support (n = 302)	259 (85.8)	65 (21.5)	148 (49.0)	124 (41.1)
Social (n = 82)	68 (82.9)	9 (11.0)	14 (17.1)	41 (50.0)
Advocacy (n = 79)	24 (30.4)	2 (2.50)	42 (53.2)	8 (10.1)
Treatment (n = 28)	12 (42.9)	4 (14.3)	6 (21.4)	7 (25.0)
Sales (n = 5)	2 (40.0)		2 (40.0)	2 (40.0)
Fundraising (n = 4)			2 (50.0)	

3.4.2. Administrators screen prospective members

As described earlier, the target membership was determined from the group name or description. In some groups (80/500, 16%), potential members had to demonstrate specific demographics to qualify for membership (e.g., be an autistic mother) by writing an introductory note to the administrator, providing a link to their Facebook profile, or submitting the pending members questionnaire. The administrator of the group assessed the prospective member's application against the stated demographic before approving or declining membership for these groups.

3.4.3. Mandatory or assumed geographical location of members

An assumed or mandatory geographical location for members was provided in 42.8% of the groups (214/500). For example, one Irish group stated that they would check prospective member Facebook profiles and residential location before adding them to the group. A preferred residential location for members was implied when the group name or description included a place name.

3.4.4. Group etiquette in descriptions

Explicit group etiquette concerning what may (or may not) be discussed or posted within groups applied to 36.4% (182/500) of all group stated purposes. Many of the support groups (124/302, 41.1%) specified group etiquette. Some specifically invited their members to "vent" (67/302, 22.2%), others emphasised that respect for other group members was important (54/302, 17.9%). For example, some group etiquette banned bullying, or any discrimination based on ability (or disability), gender, sexual orientation, or religion. The ideas about respect were reinforced by the frequent use of etiquette rules in the group descriptions. In some cases, members were banned from discussing a controversial topic in the autism community (e.g., vaccines) to deter flame wars. Some autistic social groups offered specific advice about social media etiquette such as: frequency of individual posts (e.g., [Aspie Gamers II \(2017\)](#) advises members that they may "post YouTube channels (if they have gaming videos), but no more than once every two weeks"); discussion topics (e.g., no talk about sex); acceptable contact with other members (e.g., don't contact other members for dates); and language (e.g., no rhetorical questions).

3.4.5. Group etiquette for different stakeholder groups

Group etiquette sometimes targeted a stakeholder group. Some groups with a target membership of autistic people which specifically invited neurotypical people to join (31/117, 26.5%), specified that neurotypical members must respect autistic people's views when posting. For example, [Aspie Adults \(ca. 2017\)](#) state: "If you are an NT friend/family of someone on the spectrum you can join the community but are asked to limit your participation to questions - not criticism". In a similar fashion, groups with a target audience of neurotypical partners which allowed autistic members (3/13, 23.1%) also provided group etiquette. For example, group etiquette for a support group of neurotypical partners advised that autistic people may "respectfully share any valuable insightful advice and support" to the neurotypical group members ([A Place of Support for Partners of adults with Aspergers / Autism, ca. 2017](#)).

3.4.6. Use of people-first and identity-first language

Of the groups which targeted autistic people, 77.8% (91/117) used identity-first language in their group names and descriptions (i.e., autistic person, Aspie). [Table 3](#) shows that for groups where the target membership was autistic, the three most frequently applied terms used to describe autistic people were Aspie (73/117, 62.4%), followed by autistic (16/117, 13.7%), and Aspergers (11/117, 9.4%). For groups which targeted parents and families, 58.2% (167/287) used person-first language to refer to autistic people in the group names and descriptions. For the groups whose target membership was parents and families, the three most highly used terms to describe autism were "with autism" (96/287, 33.4%), followed by "with ASD" (30/287, 10.5%), and autistic (16/287, 10.1%). Note that when Asperger was used it was in identity-first language in terms such as "Asperger women", or "Asperger children". Use of the term autistic was commonly used by both the autistic groups and parents and family groups.

Of the groups that were identified as being support groups which targeted neurotypical mothers, 73.1% (19/26) described themselves as "autism moms" or some local variant of this term (e.g., mum, mother, or mammy).

4. Discussion

The pervasive adoption of social media amongst the global population, and the increasingly seamless flow between offline and

Table 3

Language Used to Describe Autistic People by Autistic and Neurotypical Groups (Percentage of the Target Membership Shown in Parentheses).

Language type	Term	Target membership			
		Autistic (n = 117)		Parents and family (n = 287)	
Identity first language	Aspie	73	(62.4)	13	(4.5)
	Asperger	2	(1.7)	4	(1.4)
	ASD			8	(2.8)
	Autistic	16	(13.7)	29	(10.1)
Person first language	ASD	2	(1.7)	30	(10.5)
	Aspergers	11	(9.4)	16	(5.6)
	Disability			3	(1.0)
	Autism	4	(3.4)	96	(33.4)
	On the spectrum	6	(5.1)	22	(7.7)
Did not describe autistic people		3	(2.6)	66	(23.0)

Note. There were 69 groups which referred to autism as a condition but did not use any terminology to refer specifically to autistic individuals, e.g., the group [Cypress Autism & Neurodiverse Support Group \(CANS\) \(ca. 2017\)](#) had a description of ‘A parent-led support group, located in Cypress, Texas.

online communication means that understanding how and why social media is used is an important endeavour for researchers and practitioners. Developing an understanding of how the autism community uses Facebook groups is important so that advocates, researchers and practitioners can consider the implications of using Facebook as a health resource, particularly for social support. This research constitutes a preliminary study to examine the nature of Facebook groups related to autism and explore the intended use of these groups by the autism community. A total of 905,655 Facebook users were identified as members of the 500 autism groups. The first research question examined the stated purposes of Facebook groups and found that they are intended to be used for six main purposes: support, social networking, advocacy, discussion and promotion of various treatments and therapy, sales, and fundraising. The second research question found that the three most commonly targeted membership categories across all purpose categories of autism groups on Facebook were parents and families of an autistic person autistic people, and women. The third research question examined characteristics of the groups and found that the clear majority of all groups had a privacy setting of closed.

4.1. Support seeking on Facebook

This study found that the majority of autism groups on Facebook were support groups intended to provide emotional support through the narrative sharing of stories. The groups also provided an online space to share information and advice. Groups with a stated purpose of support were not only the most common, but also retained the most members, so it is possible that the current participation reflects some degree of perceived benefit. However, whilst the Internet provides autistic individuals and their families with an opportunity to converse with other autism community members across the globe, almost half of the groups indicated a specific geographical location for their target members which was either assumed or mandatory. The geographical restrictions placed on almost half of the support groups suggest that some localised content may be included or important to these groups. [Mohd Roffeei et al. \(2015\)](#) found that autism Facebook support group members in Malaysia were organising offline meetings and events. It could be that the purpose of the geographical restrictions in this sample was to achieve this.

Given the benefit that parents report from sharing emotional support and narrative stories about their experiences in a group setting ([Bitsika & Sharpley, 1999](#); [Burton-Smith, McVilly, Yazbeck, Parmenter, & Tsutsui, 2009](#)), it was not surprising that parents and families were the most frequently targeted members. The asynchronous nature of these online support groups may also be attractive to parents who face barriers such as lack of childcare or transportation to attending offline support groups ([Clifford & Minnes, 2013](#)). Most parent and families support groups were closed, most likely because the main stated purpose of the support groups was the provision of emotional support through member sharing of stories, frustrations, and challenges relating to their children.

[Pellicano, Dinsmore, and Charman \(2014\)](#) found that autistic adults in the United Kingdom wanted research prioritised which aimed to help people gain skills to manage in a neurotypical world. This interest in working out how to successfully negotiate the neurotypical world was reflected by the stated purpose of many of the autistic support groups.

4.2. Autistic socialising on Facebook

Groups which intended to be online spaces to facilitate social companionship for autistic people were the second most common type of group despite having relatively small numbers of members. Similar to older versions of autistic socialising such as mailing lists (see [Gillespie-Lynch, Kapp, Shane-Simpson, Smith, & Hutman, 2014](#); [Sinclair, 2005](#)) the Facebook social groups aimed to provide opportunities for autistic people to communicate online about their interests with like-minded people. An overwhelming majority of

social groups which targeted autistic people were closed. Given that the autistic social groups invited members to talk about their interests and often described themselves as being “safe” places for discussion, having a privacy setting of closed would help support the goal of ensuring that communications remained private.

4.3. *Negotiating autistic and neurotypical identities*

In some groups, demographic information for members was not only specified, but checked by the administrator before potential members were admitted. This could be to increase homogeneity in the group to increase group cohesion. For some groups where the demographic specified autistic or neurotypical, the aim could be to create separate autistic and neurotypical spaces. Bertilsdotter et al. (2013) found that autistic people valued separate online autistic spaces as places to develop a sense of community and identity outside a neurotypical dominated world.

This was further reflected in the use of terminology by the groups. Kenny et al. (2016) found that most autistic adults preferred identity-first language. In this study, most groups targeting autistic people also used identity-first language although the term autistic was commonly used by both autistic groups and families and/or parent groups. Of the groups that were identified as being support groups which targeted neurotypical mothers, most described themselves as “autism [moms].” The autism [parent] terminology can be problematic as it is offensive to some autistic people who feel that the parent is attempting to usurp their child’s autistic status (Wingert, 2015).

4.4. *Reflections and future directions*

This study used new technology to collect data through data scraping. To ensure rigour in the search methodology, a manual search confirmed the results of the algorithm. The study found that the data scrape method was more efficient than the manual search (as the algorithm found more relevant groups). The study also established that Facebook returns personalised search results to the user regardless of their use of an algorithm or manual search, and that some of the personalised results are related to the geographical location of the user.

Additionally, the key words used to find Facebook groups were chosen based on different representations of autism (e.g., Asperger’s syndrome) rather than variations of the word autism (e.g., autistic). Selection of key words for a Facebook search is crucial to the collection of the data of interest. In most databases, a truncation search which uses the root of a word followed by an asterisk (*) as a wildcard can be used to broaden search results as it will return results with any ending of that root word (Hopkins, 2017). For example, “autis*” as a search term would return results that include autism, autism spectrum disorder, and autistic. However, the Facebook search algorithm does not allow for truncated searches. For example, using autis* as a search term will return results about Indonesian autism groups in the Bahasa Indonesia language. In future studies, search terms should also include known variations of autism such as autistic. Other words and phrases that are commonly used in the field such as neurodiversity, and “on the spectrum” may also increase the number of returned groups. Nevertheless, it should be noted that not all search terms are helpful in locating autism groups. For example, even though wrong planet is not only a well-known autistic forum, but also well used colloquially, including this term in the key search terms only provided 3 out of 500 groups.

The study made conclusions about the membership of groups based on their targeted membership. Therefore, a limitation is that it is not possible to know if the targeted demographic joined the groups unless the researcher joined the groups or contacted the members. In addition, although this study describes intended purpose of groups, it does not follow that this is how they are being used or if this is what members are seeking. An extension of this research could be to interview members and administrators of groups to discover how the various aspects of group design such as the privacy settings, explicitly stated group etiquette and described targeted membership were influential in attracting that targeted membership, and also if the groups are being used in the way they are intended.

Social media increasingly plays a part in human daily interaction. This is the first time that researchers have attempted to provide an overview in understandings of Facebook groups and their place within the autism community. The findings that separate and shared neuro-spaces that are being negotiated within Facebook groups could stimulate critical discussion around the autism community’s engagement with social media. In addition, the large participation in parent and family support groups suggest that Facebook may play an important role in the support structure of parents and families. The large number of autistic social groups suggest that Facebook may also play an important role in providing social networking opportunities for autistic people.

Conflict of interest

We wish to confirm that there are no known conflicts of interest associated with this publication and there has been no significant financial support for this work that could have influenced its outcome.

We confirm that the manuscript has been read and approved by all named authors and that there are no other persons who satisfied the criteria for authorship but are not listed. We further confirm that the order of authors listed in the manuscript has been approved by all of us. We confirm that we have given due consideration to the protection of intellectual property associated with this work and that there are no impediments to publication, including the timing of publication, with respect to intellectual property. In so doing we confirm that we have followed the regulations of our institutions concerning intellectual property.

We understand that the Corresponding Author is the sole contact for the Editorial process (including Editorial Manager and direct communications with the office). She is responsible for communicating with the other authors about progress, submissions of

revisions and final approval of proofs. We confirm that we have provided a current, correct email address which is accessible by the Corresponding Author and which has been configured to accept email from u1029130@umail.usq.edu.au.

Acknowledgements

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

Appendix A

Codebook to Explore Autism Group Purpose, Target Membership, Group Characteristics in Group Name and Group Description

Object Level Category	Attribute level categories	Possible Values					
Group purpose	Unidentifiable or missing	No	Yes				
	Support	No	Yes				
	Social	No	Yes				
	Advocacy	No	Promote Vaxxed	Awareness			Instrumental assistance
	Treatment	No	Treatment	Chemical			Unspecified/unidentifiable
	Sales	No	Buy- swap-sell	Jewellery			
Target Membership	Fundraising	No	Yes				
	Gender	Not specified	Female	Male			
	Autistic / NT Status	Not specified	Autistic	NT			
Group characteristics	Relationship to autistic person	Not specified	Partner	Parent	Family	Professionals	
	Member screening?	No	Yes				
	Group Etiquette	No	Yes				
	Use the word vent	No	Yes				
	Use the word respect	No	Yes				
	Geographical location indicated or required	No	Yes				
	Disability-first words used	No	ASD	Asperger	Aspie	Autism [mom]	Autistic
	Person-first words used	No	ASD	Aspergers	Autism	Disability	On the spectrum
No words used to describe autistic people	No	Yes					

Codebook to Explore Autism Group Privacy Settings and Membership

Object Level Category	Attribute level categories	Possible Values	
Privacy setting	Privacy setting	Closed	Open
Group members	Member count	Quantitative value	

References

A Place of Support for Partners of adults with Aspergers / Autism (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/partnersofadultswithaspergers/?ref=br_rs.

Aspie Adults (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/201162106715104/?ref=br_rs.

Aspie Gamers II (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/AspieGamersII/?ref=br_rs.

Aspie Pug Family (2017). *Group description [Facebook group]*. Retrieved July 2, 2017, from https://www.facebook.com/groups/1491306607763257/?ref=br_rs.

Autism Support Central Texas (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/1721499118068882/?ref=br_rs.

Autistic Hoya (2011). *The significance of semantics: Person-first language: Why it matters [Blog post]*. August 4, Retrieved from <http://www.thinkingautismguide.com/search?q=the+significance+of+semantics>.

Bagatell, N. (2010). From cure to community: Transforming notions of autism. *Ethos*, 38(1), 33–55. <https://doi.org/10.1111/j.1548-1352.2009.01080.x>.

Bender, J. L., Jimenez-Marroquin, M. C., & Jadad, A. R. (2011). Seeking support on Facebook: A content analysis of breast cancer groups. *Journal of Medical Internet Research*, 13(1), e16. <https://doi.org/10.2196/jmir.1560>.

Bertilsdotter Rosqvist, H., Brownlow, C., & O'Dell, L. (2013). Mapping the social geographies of autism – online and off-line narratives of neuro-shared and separate spaces. *Disability & Society*, 28(3), 367–379. <https://doi.org/10.1080/09687599.2012.714257>.

Bitsika, V., & Sharpley, C. (1999). An exploratory examination of the effects of support groups on the well-being of parents of children with autism-I: General counselling. *Journal of Applied Health Behavior*, 1(2), 16–22. Retrieved from http://s3.amazonaws.com/academia.edu.documents/42948526/An_exploratory_examination_of_the_effect20160222-27853-t7nrcu.pdf?AWSAccessKeyId=AKIAIWOWYYGZ2Y53UL3A&Expires=1489498694&Signature=J95tGvp70Vb%2BuHHpCDkA5fdPJPQ%3D&response-content-disposition=inline.

Boshoff, K., Gibbs, D., Phillips, R. L., Wiles, L., & Porter, L. (2016). Parents' voices: "why and how we advocate". A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784–797. <https://doi.org/10.1111/cch.12383>.

Braithwaite, D. O., Waldron, V. R., & Finn, J. (1999). Communication of social support in computer-mediated groups for people with disabilities. *Health Communication*, 11(2), 123–151. https://doi.org/10.1207/s15327027hc1102_2.

Brownlow, C., Bertilsdotter Rosqvist, H., & O'Dell, L. (2015). Exploring the potential for social networking among people with autism: Challenging dominant ideas of 'friendship'. *Scandinavian Journal of Disability Research*, 17(2), 188–193. <https://doi.org/10.1080/15017419.2013.859174>.

- Burke, M., Kraut, R., & Williams, D. (2010). Social use of computer-mediated communication by adults on the autism spectrum. *2010 ACM Conference on Computer Supported Cooperative Work*, 425–434. <https://doi.org/10.1145/1718918.1718991>.
- Burton-Smith, R., McVilly, K. R., Yazbeck, M., Parmenter, T. R., & Tsutsui, T. (2009). Service and support needs of Australian carers supporting a family member with disability at home. *Journal of Intellectual & Developmental Disability*, 34(3), 239–247. <https://doi.org/10.1080/13668250903103668>.
- Chamak, B. (2008). Autism and social movements: French parents' associations and international autistic individuals' organisations. *Sociology of Health & Illness*, 30(1), 76–96. <https://doi.org/10.1111/j.1467-9566.2007.01053.x>.
- Chuang, K., & Yang, C. C. (2010). *Social support in online healthcare social networking*. *Conference 2010 Papers*. Retrieved from <https://www.ideals.illinois.edu/handle/2142/14927>.
- Clifford, T., & Minnes, P. (2013). Who participates in support groups for parents of children with autism spectrum disorders? The role of beliefs and coping style. *Journal of Autism and Developmental Disorders*, 43(1), 179–187. <https://doi.org/10.1007/s10803-012-1561-5>.
- Cowling, D. (2017). *Social Media Statistics Australia may 2017 [blog post]*. June 1, Retrieved from <https://www.socialmedianews.com.au/social-media-statistics-australia-may-2017/>.
- Cypress Autism & Neurodiverse Support Group (CANS) (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/1869397843274791/?ref=br_rs.
- Davidson, J. (2008). Autistic culture online: Virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, 9(7), 791–806. <https://doi.org/10.1080/14649360802382586>.
- Dekker, M. (2000). *On our own terms: Emerging autistic culture*. Retrieved May 13, 2017, from <http://www.autscape.org/2015/programme/handouts/Autistic-Culture-07-Oct-1999.pdf>.
- Ellison, N., Steinfield, C., & Lampe, C. (2006). Spatially bounded online social networks and social capital: The role of facebook. *Annual Conference of the International Communication Association*. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.85.5541&rep=rep1&type=pdf>.
- Eysenbach, G., & Till, J. E. (2001). Ethical issues in qualitative research on internet communities. *British Medical Journal*, 323, 1103–1105. <https://doi.org/10.1136/bmj.323.7321.1103>.
- Facebook (2017a). *Facebook, Inc. (FB) First Quarter 2017 Results Conference Call*. Retrieved from https://s21.q4cdn.com/399680738/files/doc_financials/2017/Q1-17-Earnings-transcript.pdf.
- Facebook (2017b). *Stats [Facebook newsroom]*. Retrieved October 13, 2017, from <https://newsroom.fb.com/company-info>.
- Facebook (2017c). *What are the privacy settings for groups? [Facebook Help Centre]*. Retrieved July 5, 2017, from <https://www.facebook.com/help/220336891328465>.
- Fight Autism & Win Detoxing Kids (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/fightautismandwin/?ref=br_rs.
- Gillespie-Lynch, K., Kapp, S. K., Shane-Simpson, C., Smith, D. S., & Hutman, T. (2014). Intersections between the autism spectrum and the internet: Perceived benefits and preferred functions of computer-mediated communication. *Intellectual and Developmental Disabilities*, 52(6), 456–469. <https://doi.org/10.1352/1934-9556-52.6.456>.
- Greenwood, S., Perrin, A., & Duggan, M. (2016). *Social media update 2016*. Retrieved from Pew Research Center <http://www.pewinternet.org/2016/11/11/social-media-update-2016/>.
- Hopkins, J. (2017). *Search databases like a pro: Truncation and wildcards*. Retrieved October 7, 2017, from <http://researchguides.ben.edu/c.php?g=261618&p=1747799>.
- Huws, J. C., Jones, R. S. P., & Ingledew, D. K. (2001). Parents of children with autism using an email group: A grounded theory study. *Journal of Health Psychology*, 6(5), 569–584. <https://doi.org/10.1177/135910530100600509>.
- IonCleanse by AMD for ASD (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from https://www.facebook.com/groups/IonCleansebyAMDforASD/?ref=br_rs.
- Jordan, C. J. (2010). Evolution of autism support and understanding via the world wide web. *Intellectual and Developmental Disabilities*, 48(3), 220–227. <https://doi.org/10.1352/1934-9556-48.3.220>.
- Kemp, S. (2017). *Digital in 2017: Global overview [Blog post]*. January 25, Retrieved from <http://wearesocial.com/sg/blog/2017/01/digital-in-2017-global-overview>.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442–462. <https://doi.org/10.1177/1362361315588200>.
- Krippendorff, K. (2004). *Content analysis: An introduction to its methodology* (2nd ed.). Thousand Oaks, CA: Sage Publications Inc.
- Landers, R. N., Brusso, R. C., Cavanaugh, K. J., & Collum, A. B. (2016). A primer on theory-driven web scraping: Automatic extraction of big data from the internet for use in psychological research. *Psychological Methods*, 21(4), 476–492. <https://doi.org/10.1037/met0000081>.
- Machin, T., Jeffries, C., & Machin, M. A. (2014). Motives for Facebook use in an Australian sample. *28th International Congress of Applied Psychology*, 1, 209. Retrieved from <http://pixabay.com/en/facebook-connection-social-network-76531/>.
- Mohd Roffeei, S. H., Abdullah, N., & Basar, S. K. R. (2015). Seeking social support on Facebook for children with autism spectrum disorders (ASDs). *International Journal of Medical Informatics*, 84(5), 375–385. <https://doi.org/10.1016/j.ijmedinf.2015.01.015>.
- Moran, P.-J. (2014). *Living on the wrong planet [Blog post]*. October 14, Retrieved from <https://www.aspergerstestsite.com/1521/living-wrong-planet/>.
- NCDA Executive Director's Corner (2017). *Group description [Facebook group]*. Retrieved June 27, 2017, from <https://www.facebook.com/groups/execdirmcda/>.
- Neuendorf, K. A. (2017). *The content analysis guidebook*. The content analysis guidebook Retrieved from (2nd ed.). Los Angeles, CA: Sage Publications Inc. <http://academic.csuohio.edu/kneuendorf/SkalskiVitae/SkalskiNeuendorfCajigas17.pdf>.
- Novak, M., & Spilleer, G. (2017). *Two billion people coming together on Facebook [Facebook newsroom]*. June 27, Retrieved from <https://newsroom.fb.com/news/2017/06/two-billion-people-coming-together-on-facebook/>.
- Offit, P. A. (2008). *Autism's false prophets*. Retrieved from Columbia University Press <http://ebookcentral.proquest.com.ezproxy.usq.edu.au/lib/USQ/detail.action?docID=908183#>.
- Pellicano, E., Dinsmore, A., & Charman, T. (2014). What should autism research focus upon? Community views and priorities from the United Kingdom. *Autism*, 18(7), 756–770. <https://doi.org/10.1177/1362361314529627>.
- QLD Autism Group (2017). *Group description [Facebook group]*. Retrieved July 2, 2017, from https://www.facebook.com/groups/5445678633/?ref=br_rs.
- Query, J. L., & James, A. C. (1989). The relationship between interpersonal communication competence and social support among elderly support groups in retirement communities. *Health Communication*, 1(3), 165–184. https://doi.org/10.1207/s15327027hc0103_3.
- Reinke, J. S., & Solheim, C. A. (2015). Online social support experiences of mothers of children with autism spectrum disorder. *Journal of Child and Family Studies*, 24(8), 2364–2373. <https://doi.org/10.1007/s10826-014-0039-9>.
- Searing, B. M. J., Graham, F., & Grainger, R. (2015). Support needs of families living with children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(11), 3693–3702. <https://doi.org/10.1007/s10803-015-2516-4>.
- Sinclair, J. (2005). *Autism Network International: The development of a community and its culture*. Retrieved from http://www.autreat.com/History_of_ANI.html.
- Wakefield, A. (2016). *Vaxxed: From cover-up to catastrophe*. Retrieved from USA: Cinema Libre Studio. <http://vaxxedthemovie.com>.
- Whiting, A., & Williams, D. (2013). Why people use social media: A uses and gratifications approach. *Qualitative Market Research an International Journal*, 16(4), 362–369. <https://doi.org/10.1108/QMR-06-2013-0041>.
- Wingert, S. (2015). *Why I call myself an "Autism Mom" [Blog post]*. Retrieved from <https://www.autismspeaks.org/blog/2015/10/01/why-i-call-myself-autism-mom>.
- Zhao, S. (2014). *Content analysis of Facebook pages: Decoding expressions given off*. London: Sage Publications Ltd <https://doi.org/10.4135/978144627305013511031>.