

Socialization of People with Autism Through Social Networks

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Abstract. People with autism spectrum disorder have different levels of impairment regarding to communication, interaction, and imagination - three social skills necessary to engage in face-to-face interaction. One way to possibly overcome these inabilities is to seek for online communities where they can express themselves freely without being judged for their appearance or difficulty of eye gazing and talking conventionally. Although there are other implications to consider, as the ones related to online security or bullying, there are social skills which could be better learnt through these communities. In this paper we review this relatively new way of social organization and we discuss the current gains and possible prospects.

Keywords: Autism and social abilities · ASD and social networks · Online communities and autism

1 Introduction

Online communities have been created in online social networks for different purposes. A basic search about autism on the most used open access online social networks, such as facebook, tumblr and blogger, will show that there are many existing communities for parents, therapists and people with autism spectrum disorder (ASD). ASD [1, 2] is a condition that affects people's abilities to communicate, interact and imagine, three social abilities necessary to engage in face-to-face interaction. Whoever lives or works with a person with this condition continuously seeks for information and support, and that could be partially supplied by these communities, as this review is going to show.

Prior to the beginning of this review, on a random free exploration of some evidence of online communities created specifically for autistic persons, we found a few that have been created within specific contexts, as it is the case described in the ethnographical study about Autcraft (a community for Minecraft for autistic adolescents) in [3] and the ones dedicated for adults as described in [4]. These communities have been very successful in providing a space for people on the autism spectrum to talk about their feelings and thoughts. What is interesting about these communities is that they were created for a very specific purpose and turned out to be helpful in building ties of friendship among their participants. In a way of speaking, they changed their main reason of being a community of practice to be a group therapy space.

Autistic persons, regarding their level of difficulties with social abilities, have a unique way of thinking and learning. The best description is in Temple Grandin's report [5] where she explains her own process of thinking as a collection of instant photo frames. If one is missing, the thinking process is not complete. Usually, an autistic person is a visual thinker, what makes sense when one considers how many autistic persons have mastered the use of electronic visual devices as computers and smartphones. In that case, for parents and therapists to think about improving their social abilities using a virtual space as a simulation for the "real world" is worth a try. Nevertheless, the topic demands a thorough review and discussion about the risks underlying it.

Given the context for this review, before even start to brainstorm for keywords, we have defined target categories of online networks based on [6]. Calvão defines social networks depending on the level and intention of message exchange among participants. In this work, we use the term *communities of practice (i)* for those social networks restricted to subscribed participants directed to a specific topic. We call a *complete social network (ii)* like Facebook, an environment containing micro blog, chat, email, forum, and news feed. Finally we call a *video driven social network (iii)* when subscribers usually are consumers of contents, and comments are only occasionally made by other users who watch those videos [7], that is the case of YouTube.

In this article we evaluate how people in the autism spectrum and/or their relatives have been using each of these categories of social network, and discuss specific issues like the technical needs of interface adaptation especially of types *(i)* and *(ii)* of social networks, as well as broader aspects like online inclusion of autistic people and possible impacts on their social behaviour.

2 Method

The systematic review used in this work is based on [8]. This method suggests the addition of more studies to complement the automatic literature review. We also intended to include some online communities in this review, but since there are so many online communities on Facebook only, we would not have enough time to do a proper filtering and compare results we decided to postpone that analysis.

The nature of this review is to carry out comparative studies on ways autistic people to engage in a virtual social network. For this reason, aiming at clarifying our research questions and finding out the keywords for search the electronic library collections, we did a mind map, showed on Fig. 1.

In Fig. 1 there is a connection between persons with and without ASD. Their connection is represented with a dotted line because that bridge has not been completely built yet, i.e. both groups lack clues for more successful interaction. Social Networks are at the centre of the research. Results depend on efforts for achieving a better use of these networks in communities, complete social networks or video social networks. At last, we also were searching for reports about the use of socialization techniques in or for social networks.

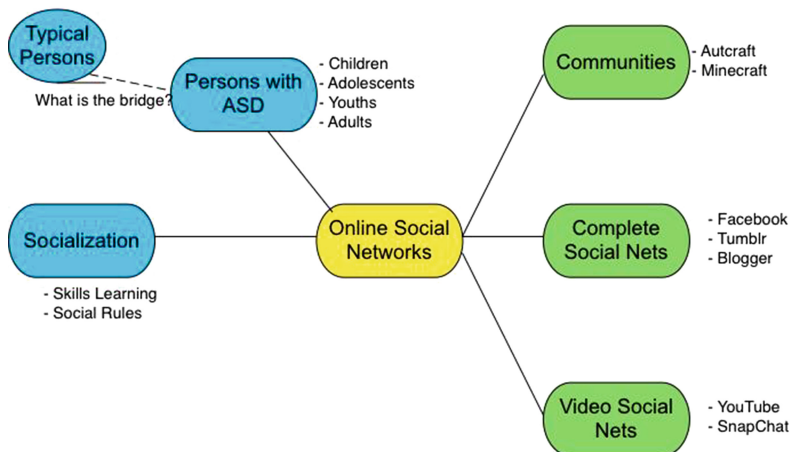


Fig. 1. Mind Map for defining questions and search terms

2.1 Review Details

Based on our mind map and first exploratory analysis, we raised three questions: (Q1) Did individuals with active participation in any social network show improved face-to-face social abilities after starting to use the network? (Q2) What are the benefits of using social networks? (Q3) Are there risks especially for people with ASD in using social networks? If so, what are they? We will show on the results section which questions were addressed by each set of papers.

From the questions above, this review objective is to compare case studies, software proposals, technology-mediated approaches and reports on the usage of online social networks by persons with ASD and their relatives in order to draw a prospective view about of the connection between autism and social networks.

The inclusion criteria are: (C1) paper's main argument is about autistic people's social abilities within an online community; (C2) research techniques used are still recent; (C3) preferably about the use of social networks (private or open) by autistic adolescents. Exclusion Criteria: (E1) publication is before 2011. To include a publication before 2011, it is only the case if the title matches exactly all the search keywords (results list and title exam); (E2) Books, indexes and editorials (results list exam); (E3) Keywords do not sufficiently match the topic (title exam).

2.2 Libraries Datasets and Extraction

The first author defined the keywords: autism, "social network", "virtual community", socialization, "face-to-face interaction" and depending on the library, changed to its other appearances as *communit**, *network** or alternating with "interaction". The libraries searched were: IEEE, ACM, PubMed, Springer, Scopus, and Science Direct.

Keywords and the first search strings candidates were defined in November, 2015. Each library has specific rules to search the dataset, and we intended to make our string

Table 1. Paper extraction and application of filters within criteria

Dataset	Results	1st filter	2nd filter	Abstracts	Total read
IEEE	40	22	17	13	4
ACM	123	96	51	21	10
PubMed	4	2	2	2	0
Springer	778	11	11	9	6
Scopus	19	4	2	2	2
Science Direct	103	16	16	16	3
	1067	151	99	63	25

as more general as it could be so we could refine other parameters such as year of publication after yielding the first search results. Table 1 shows how our search extraction was conducted considering the criterion for inclusion and exclusion in our first, second and third filter (abstract).

One paper from IEEE library was outside of C1 for being from 2010, but the keywords matched completely. Consequently, it made part of the review. On ACM the same happened with two papers. On PubMed two passed the first and second filter but the abstracts were out of context. Springer and Science Direct were completed exclusively on the web. Two filters were applied in parallel, remaining only the selected abstract to be read. As the first author does not have access to Springer, she contacted the nine authors responsible for the selected papers. Six of them provided their proof copy. Finally, two of the pre-selected papers from Scopus were already on ACM.

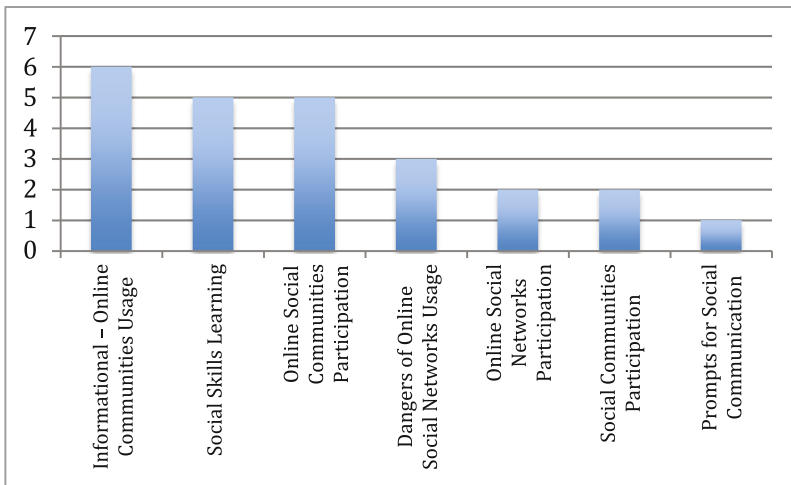


Fig. 2. Amount of publication per category

3 Results

Although the extracted publications had very diverse categories of study (7 defined as shown in Fig. 2) the data for the studies concentrates mostly on the United States, followed by Australia, New Zealand and UK, with only two papers using data from worldwide, as shown in Fig. 3.

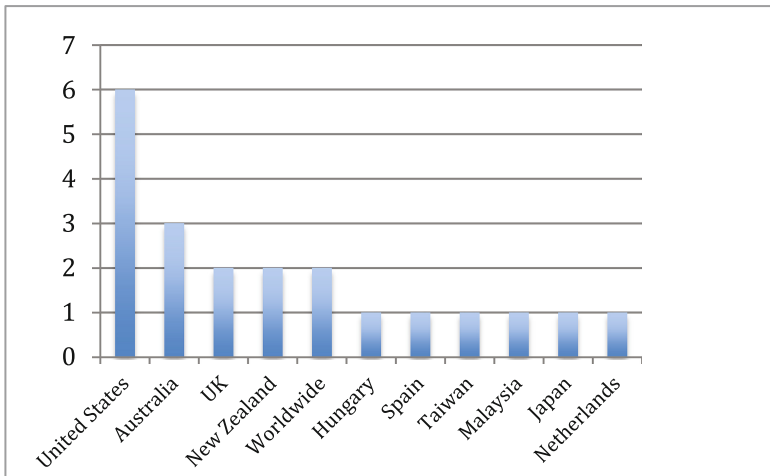


Fig. 3. Countries where population samples used in the publication are from

Regarding publication categories, the most frequent was “Informational – Online Communities Usage”. In this category, there are papers that present arguments for the use of online social networks but do not have any case or empirical study about its use by ASD persons. This category is followed closely by “Social Skills Learning” and “Online Social Communities Participation”. Papers in the “Social Skills Learning” group present computational tools for autistic children, adolescents or youth to learn specific social skills while practicing them with their peers during practice sessions. In the “Online Social Communities Participation” group, there are papers on the usage of online communities by persons with autism or their relatives. It is worth to mention that we are using the classification presented on the introductory session for these categories. The communities mentioned in these papers are communities of practice as in definition (i). Some of them work on a bigger social network but are members-only.

Regarding the remaining four categories, papers in the “Dangers of Online Social Networks” point out the intrinsic risks that more vulnerable users, as persons with autism, may find when sharing their information with all kinds of people. Among these are: bullying increasing risks, turning into cyberbullying, asking and receiving advice from malicious people, etc. “Online Social Networks Participation” contains papers about the current usage of complete social networks (ii) mainly by relatives of persons with autism who use them as supporting groups. A couple of papers are about how

Table 2. Classification for the extracted papers

Title	TP	Q	Category
Accessing Peer Social Interaction: Using Authorable Virtual Peer Technology as a Component of a Group Social Skills Intervention Program	JP	Q3	Social Skills Learning
VR4VR: Vocational Rehabilitation of Individuals with Disabilities in Immersive Virtual Reality Environments	CN	Q3	Social Skills Learning
MyCalendar: Fostering Communication for Children with Autism Spectrum Disorder Through Photos and Videos	CP	Q1	Prompts for Social Communication
Investigating the usability of social networking sites for teenagers with autism	CN	Q1	Online Social Networks Participation (Adolescents)
SocialMirror: Motivating Young Adults with Autism to Practice Life Skills in a Social World Collaborative Technologies for Children with Autism	EA	Q2	Social Skills Learning
Imagine That: Creating a ‘Third Space’ for Young People with High Functioning Autism through the Use of Technology in a Social Setting	CN	Q2	Social Communities Participation (Adolescents)
Overcoming Data Scarcity of Twitter: Using Tweets as Bootstrap with Application to Autism-Related Topic Content Analysis	CP	Q2	Informational – Online Communities Usage
Making “Safe”: Community-Centered Practices in a Virtual World Dedicated to Children with Autism	CP	Q2	Online Social Communities Participation (Adolescents)
Investigating the Use of Circles in Social Networks to Support Independence of Individuals with Autism	CP	Q1	Online Social Communities Participation (Youth)
Collaborative Technologies for Children with Autism	CDP	Q2	Social Skills Learning
Specializing Social Networking Services for Young Adults with Autism	EA	Q2	Informational – Online Communities Usage
Social Playware: Device-Mediated Social Interaction for Therapeutic Activities	CP	Q2	Social Skills Learning
Prospects for the Use of Multiplayer Online Games in Psychological Rehabilitation	CP	Q2	Informational – Online Communities Usage
Research into the Treatment of Autism Using Virtual Communities	CP	Q2	Informational – Online Communities Usage
Are Our Online “Friends” Really Friends?	MP	Q2, Q3	Informational – Online Communities Usage

(Continued)

Table 2. (Continued)

Title	TP	Q	Category
Online social networks and mental functioning: a case study	C P	Q2, Q3	Dangers of Online Social Networks Usage
Online social networks as a tool to support people with special needs	J P	Q1, Q2	Online Social Communities Participation
Cyberbullying among male adolescents with attention-deficit/hyperactivity disorder: Prevalence, correlates, and association with poor mental health status	J P	Q1, Q2, Q3	Dangers of Online Social Networks Usage
Seeking social support on Facebook for children with Autism Spectrum Disorders (ASDs)	JP	Q1, Q2	Online Social Communities Participation (Parents)
Interactive Digital Storytelling and HCI Techniques Applied for Edutainment in Interactive Health Projects: Analysis of Two USC's Labyrinth Projects	CP	Q2	Informational – Online Communities Usage
Do Social Networks Differ? Comparison of the Social Networks of People with Intellectual Disabilities, People with Autism Spectrum Disorders and Other People Living in the Community	JP	Q2	Social Communities Participation (Adults)
Flourishing on Facebook: virtue friendship & new social media	J P	Q2, Q3	Dangers of Online Social Networks Usage
Affective, Linguistic and Topic Patterns in Online Autism Communities	C P	Q1, Q2	Online Social Communities Participation (Adult + Parents)
Facebook Use by Persons with Disabilities	J P	Q1, Q2	Online Social Networks Participation (18+)

adults with autism cope with face-to-face communities and be active on them; this group is called “Social Communities Participation”. In the last category there is only one paper because it could not fit adequately in any other category. It is “Prompts for Social Interaction” where a computational tool is presented as an information manager for parents and the children with autism themselves to upload photos and videos within their daily agenda. It is used during classes for socialization.

Analysing the extracted publications and keeping track of the categories where case studies have been conducted, this review may not be globally representative for the whole population of autistic people. South America for instance, is not represented, as shown on Fig. 3.

Table 2 shows all the extracted papers, with its type, category and underlying question addressed for this review. JP stands for journal paper, CN for conference note,

CP for conference paper, EA for extended abstract, CDP for conference demo paper and MP for magazine paper.

4 Discussion

Regarding the extracted papers, space constraints lead us to illustrate typical issues through discussion on two exemplary categories: (a) “Informational – Online Communities Usage” and (b) “Online Social Communities Participation”.

From category (a) they all answer research question (Q2) about the benefits of using online social networks, and one of them also answers question (Q1) about the existence of any improvement on face-to-face interaction. Below there is an overview of papers from this category: In “Overcoming Data Scarcity of Twitter: Using Tweets as Bootstrap with Application to Autism-Related Topic Content Analysis” authors find trend topics related to autism on twitter. There is no distinction between provenances of posts. Parents usually post the most, and there are posts by adults with ASD, or by kids with ASD; and other may post some by any other people. - On other direction, “Specializing Social Networking Services for Young Adults with Autism” is a PhD research proposal. The author proposes a tool for question and answer (Q&A) as a result of his investigation in an online community with Asperger. His objective is to amplify autistics communication networks that pass through changes from adolescence to adulthood trying to have their needs attended. - In a more optimistic direction is the work “Prospects for the Use of Multiplayer Online Games in Psychological Rehabilitation” which proposes possible clinical applications of MOGs like Second Life to help on specific therapies and socialization. It could be used for autism, but the paper only gives suggestions and no experimental evidence. - Moving towards autism treatment, the paper “Research into the Treatment of Autism Using Virtual Communities” proposes the use of virtual communities as a space for treating autism. They used a realistic clinic model. That proposal has not been put to practice yet. First arguments seem right, but the idea of “treatment” with doctors and psychologists don’t seem to be practical or effective. - Continuing on the topic of using social networks extensively as a way to attenuate some of the difficulties of autism but already alerting for some dangers is the work “Are Our Online ‘Friends’ Really Friends?”. In this magazine article authors comment about the usage of Facebook by youths and adults with ASD as being beneficial because it empowers them with abilities for some social interaction they cannot keep in real world, and things happen there because they are able to respond to messages at their own pace and for whomever they deem to. On the other hand, this kind of interaction is dangerous, as they do not have enough experience to know who is trustworthy. They are much more vulnerable than their neuro-typical peers. The research suggests Facebook to incorporate some reputation mechanism.

Regarding category (b), the questions they address depend on the paper. It is a category with many different viewpoints. On “Making ‘Safe’: Community-Centered Practices in a Virtual World Dedicated to Children with Autism” the authors describe an immersive virtual community for adolescents with ASD and their parents called Autcraft. It has many explicit rules, with some administrative levels, involving parents and kids (10–17y). The aim is to be a safe social environment. This is the reason why

there are so many rules like “don’t talk about dating”, “treat everyone respectfully”, “no swearing”, etc. The claim is that with this sort of safe and artificial environment, kids will learn how to protect themselves in the real world. - The paper “Investigating the Use of Circles in Social Networks to Support Independence of Individuals with Autism” describes communities developed specifically for this case study, which was an experiment with three youth Aspergers to stimulate their independence through the use of a social network service, in private mode, with the app GroupMe. In this network, people create their circles, contacting people according to common topics. In the case of these youths, they created only one circle with their relatives and their main caretaker, in many cases, their mum. The experiment worked in a way to prove that it is possible to share their overdependence related to their primary caretaker among other people who can also help giving opinion about many daily topics. And they also learn to socialize in this safe environment. - More on Online Communities, “Online Social Networks as a Tool to Support People with Special Needs” is about the whole process of developing and using a social community from scratch. They conducted a pilot study for a year with patients and their contact networks in this devised online social community. Data points out that all contact networks have been strengthened among participants and they felt confident enough to share information on this space. - Further, the paper “Seeking Social Support on Facebook for Children with Autism Spectrum Disorders (ASDs)” again brings the subjects of communities for supporting parents of children with ASD. Their findings were very meaningful: Authors categorized the messages and realized the most common ones were for seeking and giving advice, what benefits directly parents who just received diagnosis for their child. - Lastly, the paper “Affective, Linguistic and Topic Patterns in Online Autism Communities” mines autistic online communities, including parents and Asperger’s communities. They found the most common words that appear in messages and categorize them according to feeling scales.

5 Conclusion

In this work we presented a systematic review on literature about autism and use of online social networks. We grouped the extracted papers on seven categories based on our mind map of the topic and questions to be addressed. Among these categories, the four concentrating most of the papers (79 %) were: Informational – Online Communities Usage; Social Skills Learning; Online Social Communities Participation; and Dangers of Online Social Networks Usage. The first two were detailed on the Sect. 4. On all categories, most of the works describe a specific requirement scenario for using (i) communities of practice or (ii) complete social networks.

It has been evidenced by this review that there are several online communities, with open and closed access. Both types have the potential to support persons with ASD to improve their social skills, but there are several other aspects raised that represent risks for autistic people. For instance, inherent dangers of using online social networks are specially alarming for young people on the spectrum because of their lack of experience in recognizing malicious intentions allied to their natural will of involvement on

networks. As suggested by Shyong in [9], social networks such as Facebook should have a reputation mechanism to reduce that risk.

Finally, there are some prospective issues to consider for immediate following work. While analyzing our data we realized that as confirmed by some of the extracted papers [9, 10], people with ASD who are “more functional” and have job placements, have reservations about exposing themselves in an autism community by fear of being discriminated, this aspect might have impacted on the amount of reports. Even when these people participate on online communities they do not want to be recognized. In that case, we intend to do a field study with some closed communities of Aspergers and Autistics in other regions and compare the data gathered from this review to check whether it was representative enough for those places as well.

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