

## SHAPING THE IMAGE OF PEOPLE WITH TRISOMY CHROMOSOME 21 IN VIRTUAL SPACE

**Luba Ślósarz**

Division of Health Humanities and Social Science  
Wrocław Medical University, Barta 5, 51-618 Wrocław, Poland  
Poland

**E-mail address:** [luba.slosarz@umw.edu.pl](mailto:luba.slosarz@umw.edu.pl)

**ORCID:** <https://orcid.org/0000-0002-0507-6595>

### ABSTRACT

**Thesis.** We are increasingly shaping our image through computer-mediated communication (CMC). In managing the image of people with trisomy chromosome 21, it is essential to use the potential of CMC to acquire networking skills for people with trisomy 21 and to make optimal use of various self-presentation techniques through active participation in the virtual community.

The article answers how the presence in the virtual community of people with trisomy chromosome 21 is marked. A lot of good practices are observed. However, mistakes are also sometimes worth knowing about and to be avoided.

**Methods.** The research material consisted of posts about people with trisomy 21 primarily on social networks and on forums and websites to which the authors of the profiles referred. The content analysis method was used for the study.

**Results.** Problems concerning the image creation of people with trisomy can be located in three areas:

- perspective (the image of the subjects is created from the perspective of third parties, such as parents);
- goal (which is mainly to seek support for children with trisomy);
- a type of self-presentation content (content is reduced to portraying people with trisomy as lovely, likable people; focus on disability-related aspects, not content in everyday life, interests).

The article also presents good image management practices and suggests directions for work on the self-presentation of people with chromosome 21 trisomy in social media.

**Keywords:** trisomy chromosome 21, self-presentation, CMC, Internet.

## SELF-PRESENTATION AND THE SPECIFICS OF COMPUTER-MEDIATED COMMUNICATION

Image management is done through self-presentation, which Mark Leary defines as: "The process of an individual controlling how they are perceived by those around them" (Leary 2007, p. 52). The subject of how we "manipulate the impression" we leave on others is relatively young. It began with the work of sociologist Erving Goffman in 1956 and, around the same time, the research of psychologist Edward Jones. Twenty years later, in 1987, a book on computer-mediated communication (CMC) was published by Starr Roxanne Hiltz and Murray Turoff Hiltz (see Gorska-Olesinska, 2008; Gurak, 2004). Over time, there has been engaging in the importance of this type of communication for various areas of human functioning, including self-presentation.

Computer-mediated communication combines what is characteristic of other types of mediated communication with what is essential for everyday communication and what is specific to the channel used.

The mediation of communication by computer (and now, more often, smartphone, tablet) has become an everyday reality. Using the Internet, one can consume, one can observe the lives of others, and one can create (Krejtz, 2009) - make one's presence felt.

Not all of our actions are directed at making a good impression. Nevertheless, self-presentation actions are often undertaken because we are generally aware of the importance of being perceived according to how we perceive ourselves. The essential characteristics of self-presentation are truthfulness, legibility, and selectivity. It can be carefully planned or completely spontaneous.

It should not be confused with manipulation.

Research shows that social networks provide an opportunity for using most of the self-presentation techniques we use *offline* (Jakubowska, 2014; 2011). Some require direct communication, while others can be used in asynchronous messages.

In the case of *online* self-presentation, in addition to the principles of effective impression control described by the researchers, the network competencies of the sender and receiver are also necessary. In describing users' network competencies, Marcin Sienko (2012, p. 135) talks about meta-literacy, which implies the ability to use previous media apparatuses and goes beyond this skill, as it also concerns understanding the social context.

In addition to the technical and social aspects, one must be linguistically competent. The Internet is changing language, often requiring the use of both a foreign language and specific Internet "slang." As David Crystal points out when writing about the changes in language caused by the impact of the Internet: "(...) language is the heart of the Internet, because Net activity is interactivity" (Crystal, 2006, p. 271).

Communication on the Internet has a specific character; it is referred to as computer-mediated communication. Initially, CMC was associated mainly with the textual exchange of information, but now other forms of expression have

appeared alongside the text; moreover, we are likely to observe a tendency to reduce the frequency of textual information and, on the other hand - to increase the use of pictorial information (Bobryk, 2001, p. 62).

Authors describing the characteristics of CMC use various classifications. The most common are anonymity and asynchronicity. How much information is revealed and how much self-presentation is revealed depends on the Internet user. For example, anonymity is reduced on social networks, but to the extent that the participant wishes.

It is helpful to know how to use the various features of CMC to shape a positive image that also contributes to the perception of *offline* people.

The article highlights opportunities to use the Internet to create a positive image of people with trisomy 21 but also points out mistakes to avoid.

### (AUTO) PRESENTATION OF PEOPLE WITH TRISOMY 21

The first question to ask in the case of image formation of people with trisomy 21 in social media is how much we can talk about self-creation and how much about image creation by third parties: relatives, parents, and foundations.

Research shows that in social media, in addition to our image, we also create the image of those close to us: our partners, parents, and most often, children (Jakubowska, 2011a). This must not be the only form of image presentation. The active presence of people with trisomy chromosome 21 online is significant. People with trisomy 21 should run their profiles and pages with the support of others. Such profiles (run by people with trisomy 21 or with more support, but still from the perspective of people with trisomy) are more credible than those run from the perspective of their caregivers. For the image of people with trisomy to be credible, it is necessary to show their everyday life, to show the world from their perspective, which is very important - to disseminate reliable knowledge about trisomy chromosome 21.

On the web, profiles run by parents primarily aimed at seeking financial support for therapy for people with trisomy chromosome 21 are typical. Such profiles are essential, but if we limit ourselves to only such messages, we will have to deal with portraying people with trisomy 21 as those who primarily need financial assistance. Instead, it is essential not to show only the problems but, as Anna Bieganowska points out, to "join the success and share the success" (Bieganowska 2015). Show as many positive examples as possible. At the same time, one should be careful not to fall into the trap of reduction: first: do not exude happiness (Bieganowska 2015), and second: do not reduce the image of people with trisomy 21 to that of nice, friendly people. The former weakens the credibility of the person's presentation; the latter shows that these people are unique in some respect, and thus the differences between them and others are emphasised. The issue of selection of the information presented is significant for self-presentation. However, selection should not be confused with reducing the image to only one feature. The approach: "happy" - "needing help" shows the ends of the continuum and is silent about what is in between them.

Another example of extremes in portrayal is showing people with trisomy as heroes (Struck-Peregończyk, 2011), which also exacerbates differences and undermines credibility. Indeed, there are extraordinary people among those with trisomy chromosome 21. As with other people, there are pleased and cheerful people, but to talk about credibility, we should also show people between the extreme points of the continuum. If we want the image to be perceived positively, we should show similarities, not differences.

Selectivity in the case of self-presentation is not about reducing features but revealing specific images depending on the situation and the "audience." Therefore, it is necessary to consider what information will be relevant to specific social groups, for example, children, caregivers, scientists, and politicians. Related to this is the issue of taking care of the third self-presentation feature, readability. When presenting the image of a person with trisomy, we should remember that this information should be understandable - it must not be "strewn" with scientific terminology. However, on the other hand, it must not simplify the problem. In addition, when we talk about presenting an image on social networks, the network competence of the person presenting the image, knowledge of netiquette (Internet etiquette), and the language used by Internet users are also essential.

### SYMBOLISM

Social media can help ensure that knowledge goes out to the public beyond the circle of people directly connected to the topic. For this to happen, information must be encoded into a message that attracts attention and encourages sharing. Thoughtful symbols make the message more attractive and allow one to express an attitude toward the issue through a single image.

An example of such an action is to encourage people to wear different coloured socks (or other coloured items) on March 21, when the day of people with trisomy chromosome 21 is celebrated, and share photos of their feet. This action is one of the most popular forms of marking the presence of people with trisomy and has been picked up by various circles on Facebook but is still, unfortunately, most publicised among those interested in the topic.

More and more messages using symbolism appear for people with chromosome 21 trisomy. In addition to the symbol of colour and diversity, the symbols of the number 21 and the straight line are also used.

Good examples with the number 21 in the background are

- 21 beautiful faces worldwide (Becker, 2015). The campaign's author asked parents worldwide to share photos and bios of children with trisomy. She then selected 21 photographs from different parts of the world;
- 21.03 as world day for people with chromosome 21 trisomy (an extra third chromosome in the 21st pair).

Another number (although less frequently used) is the number 13. This symbol is related to the number of detected features specific to people with Down syndrome.

An example of the use of number symbolism is the creation of 13 doll models

designed by Jerri McCloud based on photos of children with trisomy (campaigns-social.co.uk).

The straight line is also an interesting symbol. It refers to one of the characteristics of people with trisomy - a straight fingerprint running along the palm. An example of the use of symbolism is, among others, the #RightLineProsta campaign organised jointly by Lifetime TV and the More Loved Association, which consisted in posting online or tagged photos with a straight line drawn. Lifetime TV donated money to support people with Down syndrome for each such photo posted on social media.

Skillful use of symbolism and a professional approach to message building makes it possible to use even opposing messages ("typicality/usuality" vs. "uniqueness") for effective impression building. For example, a campaign showing the similarity of people with trisomy to other people is an action based on the symbolism of the word "teams" (syndrome). The campaign consisted of professionally taken photos of people with trisomy chromosome 21, depicting in sequence: "karaoke team," "Hollywood team," "1980s team, princess team, Messi team." The campaign's motto was "I am who I am and I have Down Syndrome" (ASDRA, 2015).

One parent, however, decided to highlight uniqueness instead of typicality. Photographer Alan Lawrence (2016) publishes a series of photos on his blog titled: "Why Does Wil Fly? ". The photos show a flying boy with trisomy, the photographer's son. Lawrence shows seemingly ordinary situations - the boy playing with his siblings, going on trips, going out for ice cream. The only unusual element is that William flies in all the photos. The professionalism, idea, and experience of the photographer give the photos a positive reception.

### **EVERYDAY LIFE AND PERSPECTIVES ON FUNCTIONING IN ADULT LIFE**

Another way is to promote positive examples, sharing videos showing good practice.

The videos must not be too generic. It is not enough to show that, for example, people with trisomy 21 can work. It is essential to show what they do, their workday, and their relationships with others.

Such good examples can be found on the website above [www.zespoldowna.info](http://www.zespoldowna.info) under the tab "My job my home," where videos show specific people who find themselves working in a hospital, in a store, in a restaurant, or such industries as fashion or business. These are people who talk about their work, their interests, and who their co-workers talk about.

Among them, for example, is Aditi Verma from India, who works in a restaurant. The young woman talks about how much her life has changed thanks to the fact that she no longer sits at home watching TV but does what she enjoys. Aditi Verma also talks about her plans for the future. Although the work suits her, she is thinking about further development. An example from the States shows Collette running her own cookie production business. In the promotional video, we see an energetic young woman who is confident and knows what she wants to achieve.

An example from Australia is the story of a girl who wanted to become a world model. With the support of those close to her, she realised her dream. Another important message is created by the story of Brina Maxino, who graduated from college and will be a teaching assistant. There are more such examples, and the important thing is that they show the variety of professional and educational paths that people with trisomy chromosome 21 can follow.

There is a lack of such examples showing the professional paths of people with trisomy in Poland. Polish portals are dominated by materials about children and helping them. Adults remain in the shadows. An exciting idea is a project in which people with trisomy chromosome 21 help serve spectators during a performance. Unfortunately, this is not a permanent job; employment lasts as long as the project. Nevertheless, it can inspire people with Down syndrome and those around them (Sladkowska, 2016).

There are also examples of people with trisomy getting involved as actors in the theatre or on TV. Unfortunately, examples from TV are not always positive, and the possibility of sharing the aired material causes many people to learn about them, even those who have not watched the film/series.

The failure to consider two key issues contributes to the spread of stereotypes. First: a person should have a predisposition to play and stand out for something. It cannot be that to play a person with a trisomy. It is enough to have a trisomy. Second: the character must be well thought out. It is a mistake to construct a character based solely on his disability.

A positive example is actress Jamie Brewer, who appears in the American Horror Story series (see Dwojnych, 2017). Depending on the season, Brewer played different characters; her role was not to play a person with trisomy but to play a character actively building the plot. The thoughtfulness of the character, combined with the talent and work of the actress, contributed to the image of a person who is admired and appreciated for what she does.

An example that deserves to be noted is the series "Downistie," which stars only people with trisomy 21. Some of the episodes of the series can be seen online. Unfortunately, this example can hardly be considered successful. Nevertheless, the idea seems to be interesting. Systematicity, commonness, and the number of episodes in serials make us get used to the characters and the problems. Soap operas, however, also have the quality of not being taken seriously, and despite all the care with which a series was made, the effect can be the opposite of what was intended. One of the most noted scenes from the series draws attention to which the heroine learns that her child may not have Down syndrome, which she experiences intensely. Such a scene could have a big message and, on its own, could be an idea for a social campaign.

### UNIVERSALITY OF INFORMATION

A growing amount of information about people with trisomy 21 and good practices contribute to creating a positive image or making the subject more familiar. However, we still may not succeed if information about people with trisomy

remains “locked up” in places intended for people interested in the problem. For example, on Facebook, we can find many groups primarily for caregivers of people with trisomy chromosome 21 (not themselves!). However, this information remains invisible to those not exposed to the topic early on. Therefore, it is essential to go out with this knowledge and weave it into various actions, cultures, and entertainment.

An interesting example is “Dating Ellen,” an excerpt from the American animated series “Family Guy.” This is a series aimed at adults, surprising with sarcastic, sometimes nonsensical humour and, notably, a top-rated series. An example is described at [www.zepoldowna.info.pl](http://www.zepoldowna.info.pl). The author of the Post reports:

“This episode features Ellen, voiced by ZD actress Andrea Fay Friedman. This episode was shown on the occasion of Valentine’s Day on television. What captured me about it? The film is aimed at adults, that’s one. Two: adult Chris arranges to meet Ellen, because people with ZD are so warm, empathetic...and it turns out that they are the same as anyone without ZD...this episode made a big impression on American viewers, and I liked it too.”

This part of the series is essential. First: because it breaks stereotypes - it takes a light-hearted approach to the problem, undermines the image of a person with trisomy 21 as exclusively lovely, and strips them of unnecessary uniqueness. Second: the series is not aimed at people interested in the subject. It is a popular series. It reaches a large number of viewers. It reaches people not looking for such knowledge, and it does so in a way that is attractive to them.

Publicising the subject is also possible through hashtags. One of them is #MyFriendsMyCommunity, a campaign organised in 2016 that urged people with trisomy 21 to talk about their lives, including their families and friends. It was also possible to use ready-made posts and post them on social media. For example, the organisers offered the following or tagged posts:

1. people with Down syndrome must be able to enjoy full and equal rights both as children and adults #MyFriendsMyCommunity # WDS16
2. Inclusive environment prepares all today’s children with and without Down syndrome for life as adults tomorrow #MyFriendsMyCommunity # WDS16
3. an inclusive environment enables adults with Down syndrome to live, work and participate with confidence #MyFriendsMyCommunity # WDS16
4. w#WDS16 encourages people with Down syndrome to speak #MyFriends-MyCommunity and let the world speak about inclusive environments

There is a lack of direct media presence for people with trisomy. Parents, siblings, and organisations usually speak on their behalf. However, there are situations where the direct voice of people with trisomy 21 will make a more significant impression. A good example is a participation in a press conference of Natalie Dedreux - a woman with Down syndrome, who personally asked a question to Angela Merkel. The question was about acquiescence in aborting pregnancies at a very late stage due to knowledge of a genetic defect in the fetus. Such questions asked without intermediaries are very impressive and raise awareness of the seriousness of the problem.

The presence of the voice of adults with trisomy in various fields, showing their capabilities and achievements, contributes to the credibility of the image and notice of the problems by a broader range of people.

### USE OF CMC FEATURES IN IMPRESSION MANAGEMENT

The last element to highlight is the use of computer-mediated communication features for the self-presentation of people with trisomy 21.

Research shows that the most optimal intensity of CMC features is observed in chat rooms. In the case of this research, it was Messenger on Facebook (Jakubowska, 2017). Well, if we compare the f2f presentation recorded on camera, with a conversation via Messenger and with the most asynchronous presentation of a person, for example, on a professional profile, the most favourable is the conversation via Messenger, less clear is the presentation on an asynchronous profile. The least favourable is the conversation recorded on camera. Therefore, CMC should be used to shape the image of people with trisomy 21. Hence it is essential for such people (and not just their caregivers or those interested in the issue) to be active online. Some self-presentation techniques are used to a limited extent or not at all. This is because there is no communication between people with trisomy and, above all, between them and others. We often deal with "self-description," especially in social campaigns, while other (very effective techniques) such as "expression of attitudes" or "social contact" are used less frequently. To use the former, people with trisomy should express their judgment on, for example, political life, fashion, and essential issues moving public opinion. To use the latter technique, one should do more interviews with, for example, well-known people raising a child with trisomy chromosome 21 and show friendships, and relationships, with people who are viewed positively.

### SUMMARY

In shaping the image of people with trisomy, symbolism plays a vital role. It is an exciting symbolism and has become the basis for many interesting projects. It is worth considering how to make participation in social actions necessary and fashionable not only among people directly related to the subject of trisomy chromosome 21.

Therefore, it is necessary to consider both the sender of the self-presentation content (more opportunities for direct self-presentation of people with trisomy) and the audience—more people not directly related to the subject. This approach will contribute to a change in perspective and make the image more credible.

The goal of shaping the image of people with trisomy should not focus on seeking support. This is an essential aspect, but if it occurs as the only aspect, it obscures other vital aspects such as: finding people with trisomy in social situations, fighting stereotypes and showing the differences between people not because of the disability but because of their interests. The goal should also include adults with trisomy in discussions about themselves.

The content presented is mostly about children and centered around Down



Syndrome's specifics. People with trisomy are portrayed as "nice," "cute," or overly resourceful. This reduction of traits can contribute to deepening stereotypes instead of combating them.

The self-presentation content of people with trisomy should be carefully prepared. One of the characteristics of CMC is that information is perpetuated and disseminated, so stumbling blocks should be as few as possible. It is essential to show the everyday life of people with trisomy and their passions, interests, and dreams, all in moderation. People with trisomy should not be required to behave as if there is no trisomy. However, neither should the importance of specific traits be emphasised because, in this way, we further emphasise the differences between them and the rest instead of focusing on the differences within them.

Summary: Among the most common mistakes in presenting the image of people with trisomy are:

- The extreme: the need for help/euphoria of happiness, heroes (Ruść, 2007);
- reducing traits to one: "likable"/"nice";
- Focusing on differences by showing "uniqueness";
- image shaping mainly by third parties
- dominant asynchronicity in messages, which negatively affects the credibility of self-presentation;
- Spreading information mainly to interested parties.

Among the pursuits that characterise effective self-presentation should be promoted:

- The active presence of people with trisomy 21 on the Internet;
- Running pages and profiles from their perspective;
- credibility and readability of the image, speaking their language about personal values and aspirations;
- Selectivity in image presentation (rather than reduction);
- sharing achievements, leaving positive traces online (Bieganowska 2015);
- Avoiding focusing on problems;
- Associating people with trisomy chromosome 21 with positive achievements, people, and events;
- Promoting good practice - sharing videos and reports showing specific examples of the employment of people;
- Creating actions to spread knowledge, involving people who do not deal with the issue daily;
- They are creating hashtags with which statements from people with trisomy chromosome 21 and their loved ones can be tagged, as well as posts promoting good practices.

An area that should be refined in Poland - is to promote the image of adults with trisomy 21. It is essential not only to prepare individuals for active participation in life but also to prepare the environment, create appropriate conditions, and develop a good reputation. Children are taken care of by their families and other

institutions. Research conducted in the UK (Skotko, Levine & Goldstein, 2011) shows that most children with trisomy 21 have high self-esteem *and* feel happy. The question is whether this feeling will fade as people with trisomy chromosome 21 enter adulthood.

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