The Internet as a space of security feeling and support for parents of a disabled child

Internet jako przestrzeń poczucia bezpieczeństwa i wsparcia rodziców dziecka z niepełnosprawnością

The aim of the article is to present the Internet as a space that provides a security feeling and support for parents of children with disabilities. The empirical research used the survey method (according to Krzysztof Rubacha), the tool was a survey questionnaire. A statistically significant group of 230 parents of children with disabilities was surveyed in several research areas. These were individual characteristics of parents seeking a security feeling on the Internet, characteristics characterizing the family and related to the use of the Internet, including forms of contact and the intensity of use. The obtained results allowed to identify the characteristics of a parent of a child with a disability who most often seeks a security feeling and support on the Internet.

Key words: Internet, family, child, disability, security feeling, support, upbringing

Celem artykułu jest przedstawienie Internetu jako przestrzeni zapewniającej poczucie bezpieczeństwa i wsparcia rodziców dzieci z niepełnosprawnością. W badaniach empirycznych zastosowano metodę ankiety (wg. Krzysztofa Rubachy), narzędziem był kwestionariusz ankiety. Przebadano statystycznie istotną grupę 230 rodziców dzieci z niepełnosprawnością w kilku obszarach badawczych. Były to cechy indywidualne rodziców poszukujących poczucia bezpieczeństwa w Internecie, cechy charakteryzujące rodzinę oraz związane z użytkowaniem Internetu, w tym formami kontaktu i intensywnością korzystania z nich. Uzyskane wyniki pozwoliły na wskazanie cech rodzica dziecka z niepełnosprawnością najczęściej poszukującego poczucia bezpieczeństwa i wsparcia w Internecie.

Słowa kluczowe: Internet, rodzina, dziecko, niepełnosprawność, poczucie bezpieczeństwa, wsparcie

Introduction

The Internet, in its essence, is based on information and its operation, and with its development it has become a space, as evidenced by the term "cyberspace" used to describe the virtual world. It is perceived by its users as a place where individual people meet. they talk to each other, create virtual communities. What is very important for this type of contacts, it is an open medium to new possibilities, meeting the expectations of users, meeting their needs, and, importantly, effectively imitating the features of the Internet and the forms possible using it contacts resulted in it spontaneously becoming a space of support for people seeking help, including parents of disabled children¹. What is called a disadvantage of online contacts, i.e. anonymity, becomes an advantage in this case. The Internet, in its essence, is based on information and its operation, and with its development it has become a space, as evidenced by the term "cyberspace" used to describe the virtual world. It is perceived by its users as a place where individual people meet. they talk to each other, create virtual communities. What is very important for this type of contacts, it is an open medium to new possibilities, meeting the expectations of users, meeting their needs, and, importantly, effectively imitating the features of the Internet and the forms possible using it contacts resulted in it spontaneously becoming a space of support for people seeking help, including parents of disabled children. What is called a disadvantage of online contacts, i.e. anonymity, becomes an advantage in this case.

There is no doubt that the loneliness of parents in dealing with the difficult situation of having a disabled child contributes to the growth of their negative emotions and social isolation. The essence of the problem is shown by an example statement from the diary of the mother of a disabled child. She writes: "Encountering a disease that no one can

¹ J. Zielińska, Internet a niepełnosprawność, Wydawnictwo Naukowe UP, Kraków 2020, s. 77.

cure and the finality of death taught me, above all, humility. Moreover, it taught me the truth that my duty as a human being and mother is to do everything in my human power. No one will take over my duties as a mother of a healthy child, no one will replace me with a sick child. And this is not resignation. It is a very deep, internal belief that this is our duty. I am wiser now with this knowledge².

In this context, it is also possible to mention user opinions from posts posted on the Dar Życia forum websites³:

- "I wanted to thank everyone (...) for the wonderful conversations, wonderful advice and comfort in moments of depression. I met wonderful people here (several people in person), I cried many times in front of the computer while reading touching stories from the lives of other families, many times I got angry when I read nonsense information, and I laughed many times while looking into the comfort book. THE GIFT IS GREAT".
- "I'm happy to be here with all the wonderful people, because although many of us are anonymous parents, everyone deserves to be recognized. I really appreciate this forum and the people who are here".

Internet as a space of security feeling and support – general comments

The research conducted on the Internet as a space for social contacts concerned, among others, the form, type and intensity of bonds between users. The question was posed: Are online communities able to develop close and strong enough relationships to be called communities? The research results did not provide a clear answer. On the one hand, it has been shown that online friendships are shallower and less emotionally involved than those made in real life, and on the other hand, relationships established online can be equal to real ones, exceeding them in importance and intensity⁴.

Castells (2007), defining a virtual community as "...a self-defining, electronic network of interactive communication organized around

² A. Chodakowska, *Mieć dziecko z porażeniem mózgowym. Pamiętnik matki*, Wydawnictwo Fundacji "Masz szansę", Lublin 1995, s. 111.

³ J. Zielińska, Internet a niepełnosprawność, Wydawnictwo Naukowe UP, Kraków 2020, s. 76.

⁴ A. Hodkinson, 'Safe spaces' – Electronic media, the internet, and the representation of disability, IARTEM *e-Journal*, 2014, Volume 6 No 1, s. 12.

shared interests or goals..." states that it may play a greater importance than that attributed to it by some researchers⁵.

He believes, and this has been confirmed by research, that even between network users connected by weak ties, there may be a phenomenon of mutual support. Online communication promotes honest and open discussion, although the relationship established in this way can be ephemeral. A virtual community is governed by different laws than a physical community and is subject to different patterns of communication and interaction, but it cannot be said to be unreal. The advantage of an individual's participation in online communities is the expansion of his or her network of social connections. Relationships established on the Internet are often referred to as "protected communication" based on its specific features, such as: open talking about the most personal problems, anonymity, the ability to regulate the frequency and intensity of contacts depending on the current need for support felt by users⁶.

Mutual support groups operating virtually have the advantage over traditional groups of eliminating elements that may have a potentially negative impact on the willingness to help another person. These include age, appearance and gender, i.e. the characteristics of the interlocutor, which significantly influence decision-making in the real world. In online communication, attitudes and interests come to the fore, often assessed as convergent based only on membership in a common online group. In order to compare the activities of Internet and classic mutual support groups, the concept of "added value of the Internet" was introduced. Grabowska (2006) defined it as: "... everything that distinguishes phenomena taking place on the Internet from analogous phenomena taking place in the real world. It is everything, what can be found on the Internet and what is not actually there, or seems subjectively better on the Internet than in reality..."⁷. The added value components in relation to the Internet as a space of social support are:

• a new form, i.e. an electronic version of the written word, allowing the message to be thought through and carefully edited, which reduces the risk of misunderstandings, and allows the person providing help

⁵ M. Castells, Społeczeństwo sieci, Wydawnictwo Naukowe PWN, Warszawa 2007, s. 362.

⁶ T. Cantelmi, L.G. Grifo, *Grupy samopomocy on-line*, [w:] T. Cantelmi, L.G. Grifo (red.), *Wirtualny umysł. Fascynująca pajęczyna Internetu*, Wydawnictwo OO. Franciszkanów "Bratni Zew", Kraków 2003 s. 128–138.

⁷ M. Grabowska, *Wartość dodana Internetu na przykładzie internetowych grup wsparcia*, [w:] J. Kurczewski (red.), *Wielka sieć. E-eseje z socjologii Intenetu*, Wydawnictwo Trio, Warszawa 2006, s. 285.

to repeatedly and thoroughly analyze the record in order to optimize the support provided,

- hyperavailability, an online group is not bound to a physical space, it is available from anywhere, at any time,
- hyperanonymity, allowing you to avoid embarrassment when sharing your most personal problems, comfort of speaking, lack of direct pressure,
- hyper-openness, anonymity promoting honesty and openness in expressing unpopular opinions, sharing secrets and problems,
- hyper-information, obtaining a compendium of knowledge on a specific topic in a very short time⁸.

The basic disadvantages of support provided via the Internet include relying on the helpers' own experiences, which may have little to do with professional knowledge, insincerity, and fraud. The Internet as a support space gives a sense of closeness to many people, and therefore a sense of social support. When assessing the benefits and threats of using the Internet as a source of information, one should be aware that the Internet should only play a complementary role to traditional methods and means of acquiring knowledge, because even the most advanced Internet tools and resources will never be able to replace real contact with a specialist. On the one hand, information obtained via the Internet may lead to exaggeration of existing problems. On the other hand, via the Internet, the user gains unlimited access to thematic content that interests him, which he can read at any time and place⁹.

Report from own research of parents of a disabled child using online forms of support

Subject and purpose of research

The subject of my own research were parents of a disabled child who use the Internet as a form of support. The diagnostic goal was to determine the individual characteristics of a parent of a disabled child who

⁸ Ibidem, s. 287.

⁹ K. Korczak, *Internet jako źródło informacji o zdrowiu i chorobach*. "Przedsiębiorczość i Zarządzanie" 2017, tom XVIII, z. 4, s. 305–310.

actively seeks support on the Internet. The cognitive goal was to determine why he is looking for support on the Internet, what forms of support he uses, considering them the most useful and with what frequency he does it.

Research problems

The main research problem was the question: What are the characteristics of a parent of a disabled child who uses the Internet as a form of support? These features were determined based on the percentage of respondents in several research areas. The first area concerned individual characteristics, including gender, age, place of residence, education, professional activity, and financial situation. The second area included the family, i.e. its structure, number of children, type and age of the disabled child. The third one concerned Internet use, i.e. computer skills, including Internet use, time, frequency and activity, and ways of finding out about online forms of support. The fourth area included online forms of support used by the respondents, their types and frequency of use. Four detailed questions were formulated for the main question:

- What individual characteristics (gender, age, place of residence, education, professional activity, financial situation) characterize a parent of a child with a disability who uses the Internet as a form of security feeling and support?
- What are the characteristics of a family (structure, number and age of children, type of disability) seeking security feeling and support on the Internet?
- What features related to the use of the Internet (computer skills, ability to use the Internet, time, frequency, activities and ways of learning about online forms of security feeling and support) characterize a parent of a child with a disability who uses the Internet as a form of support?
- What forms of online support are used and with what intensity by parents of a disabled child seeking security feeling and support on the Internet?

Due to the lack of items in the literature on the subject on the basis of which it would be possible to formulate working hypotheses, research problems remained open¹⁰.

Researchers' methods and tools

The conducted own research was based on inductive cognition and nomothetic explanations. They enable the development of statements that refer to the studied population and show the statistical order that characterizes it. They allow for the formulation of general regularities that apply to the population, as well as for building and verifying scientific theories and laws¹¹. The research process used a quantitative data collection method, which is a survey. The research tool, i.e. the survey questionnaire, was developed in accordance with the rules of methodology according to: Krzysztof Rubacha. The survey questionnaire used in our own research consisted of 20 questions, instructions for filling out information, most of them were closed questions, some of them based on a Likert scale. Several final questions were open-ended.

Characteristics of the study group

230 people participated in the research. The majority of the surveyed parents were women, approximately 90% of the respondents. They were young people. The largest group, approximately 35%, was aged 30-35. The next two equally numerous groups, each 20% of the respondents, were people aged 25-19 and 36-41. The least, 5%, were groups of people under 24 and over 48. Other individual characteristics include place of residence, education and professional activity, as well as a subjective assessment of the financial situation. In the study group, more than half of the people came from large cities, including 35% from cities with over 200,000 inhabitants. inhabitants, 20% from cities with 100-200 thousand inhabitants, in total they constituted 55% of the surveyed group. The least, 10%, lived in the countryside or in a small town, up to 10,000. inhabitants. Almost 80% of respondents had higher education, and only 5% had vocational education. In the category of professional activity, the

¹⁰ K. Rubacha, *Metodologia badań nad edukacją*, Wydawnictwa Akademickie i Profesjonalne, Warszawa 2008, s. 97–99.

¹¹ Ibidem, s. 20.

research results were divided almost equally, 45% of respondents worked full-time, 40% did not work. The financial situation of the respondents in the largest group, 45%, was described as good, extreme opinions, i.e. very good and bad, were in the minority in about 5% of the respondents.

With regard to the characteristics of the family, the research showed that the majority of the surveyed people, about 80%, create full, legally formalized families, and the largest group, about 40%, are families with one child. It is worth emphasizing that only 5% of respondents are single parents and have four or more children. This also requires appropriate analysis of why parents from large families or single parents do not use online forms of support. The largest group of respondents, approximately 40%, were families in which a disabled child was aged 1-3. The smallest group, approximately 5% each, were parents of infants and older children aged 13-18. Which also requires an appropriate comment. Almost 3/4 of the respondents were parents of a child with Down syndrome, approximately 75%. Next, epilepsy, autism spectrum disorders, cerebral palsy or lack of diagnosis of developmental problems were indicated.

Organization and course of research

The study was conducted online. A survey questionnaire was included in Google Forms, addressed to parents who have a child with a disability. Links to the survey were posted on social networking sites, especially in groups associating parents and online forums that they actively used. However, the difficulty encountered was the parents' lack of reaction to the attempt to conduct the study. This took time and it was necessary to additionally send requests to complete the questionnaire to a larger number of places than initially expected, because in each of them there were few parents who decided to participate in the study. However, there were no comments showing a negative attitude towards the request to participate in the study.

Discussion of the results and conclusions obtained during the study

The data obtained during the research, characterizing the study group, indicated that support via the Internet is mainly sought by mothers of disabled children at the age typical for having children, between 30 and 35 years of age.

These are not fathers, very young people or, for example, grandparents – these groups were the least numerous. The reasons for this state of affairs, which is particularly worrying in the context of the lack of fathers' participation, require separate analysis. Determining the individual factors defining a model parent using online forms of support: a young woman, around thirty-something, very well educated, living in a large city, with a good financial status, working professionally or not. To summarize the individual factors determining the characteristics of a parent using online forms of support: a young woman, around thirty-something, very well educated, living in a large city, with a good financial status, working professionally or not. To summarize the family factors that define a model parent who uses online forms of support is a complete family, usually having one child aged 1-3 with Down syndrome. The fact that a significant group of people looking for help on the Internet are parents of a child with Down syndrome is fully understandable for people dealing with this issue and is reflected in the literature on the subject¹². The next area examined concerned Internet use, including computer skills, Internet use, time, frequency and activity, and ways of finding out about online forms of support. Most people, approximately 85%, described their computer and Internet skills as good or very good. No one expressed an opinion: poor. Most people, approximately 60% of respondents, have been using online forms of support for one to three years. The least, about 5% longer than 3 years. About 60% of respondents sought support online on their own, either intentionally or by accident (most choices: intentionally). About 10% were the founders of websites and internet forums. About 95% of respondents used the Internet every day or almost every day as an information and communication medium, and 75% equally often to seek support in this way. More than 50% of respondents described themselves as quite or very active participants, 15% read but do not express their opinion.

The most popular form of support among the surveyed parents were discussion forums, with 100% selection. The second most frequently used form of virtual support were websites and online portals, used by almost 75% of the surveyed parents. About 40% of the surveyed people read blogs, and 25% ran their own blog. Less popular online forms of support were lists and discussion groups, used by only 15% of respondents, and online specialist services, 10% of responses. None of the respondents

¹² E. Zakrzewska-Manterys, *Upośledzeni umysłowo. Poza granicami człowieczeństwa*, Wydawnictwo UW, Warszawa 2010, s. 186.

used chat rooms or IRC. To sum up the Internet-use factors defining a model parent using online forms of support is a person who knows how to use a computer well, knows how to use the Internet, uses it actively almost every day, seeks support and information independently, mainly on Internet forums, websites and portals, operates in the up to one to three years, then the activity unfortunately decreases.

Final conclusions and postulates for practice

The research, carried out on a statistically significant group, made it possible to draw conclusions enabling, of course, with some approximation, to determine the characteristics of parents using online forms of security feeling and support:

- a young woman, around thirty-something, very well educated, living in a large city, with a good financial status, working professionally or not,
- having a complete family, usually having one child aged 1-3, with Down syndrome.
- knows how to use a computer well, knows how to use the Internet, uses it actively almost every day,
- looking for support and information on their own, mainly on internet forums, websites and portals, active for a period of one to three years, then their activity decreases.

According to Zakrzewska-Manterys (2010), who is a professor of social sciences and the mother of an adult child with Down syndrome – Wojtek, and therefore has appropriate knowledge and experience, there is a very serious problem with the quality, quantity and form of information provided to parents of children with Dawn syndrome, as well as methods of supporting development, organizational forms of care, and even legal solutions¹³. This is confirmed by the research results. They may indicate, when assessing the fact that mothers of children with Down syndrome look for support on the Internet, not immediately after the child's birth, but after several years, that the previous several years of support from both the family and the institution was insufficient.

There are several factors that make people seek help via the Internet. This is the lack of spatial barriers, contact with different people, and

¹³ Ibidem, s. 10–11.

anonymity, which in many cases makes it easier to talk openly about one's problems. In addition, using primarily the written word, which allows for much greater control of the message. Another reason why people willingly use online forms of support is the lack of debt of gratitude ¹⁴. Mutual assistance, especially among people with similar experiences or interests, is also an important element of the process of building group bonds. Therefore, the popularity of discussion forums and support groups is constantly increasing, where you can quickly and easily find someone with similar preferences or problems¹⁵. And these are the forms of support indicated by the surveyed parents. Since parents of disabled children and disabled people themselves look for support on the Internet, it is worth promoting online psychological help. Psychological assistance is defined as any professional interaction conducted over the Internet for the purpose of assisting with mental health¹⁶. Psychological help provided on the Internet includes the following types: counseling, consultation, psychoeducation, crisis intervention and health promotion. The advantages of this solution include the convenience and comfort of the person using this form of support, who can get the help they need without leaving home and at any time of their choosing. Other advantages include the speed of obtaining e-help, ease of use, saving money, anonymity, and a sense of security. Indirect contact helps reduce fear, shame and fear of being judged. However, online support also has some limitations. The most important ones include limited contact, because interlocutors do not have the opportunity to react to each other's messages on an ongoing basis, increased ability - intentional or unintentional - to create their image, which may significantly affect the ineffectiveness of contact, and Internet language, which is characterized by great carelessness and brevity. Both those providing e-support and those using it should be aware of the advantages and disadvantages mentioned. Using online help wisely and appropriately is about maximizing the benefits of online contact and minimizing the risks. To sum up, the Internet promotes cultural change and largely meets the needs of users, ranging from elementary needs

¹⁴ P. Wallace, *Psychologia Internetu*, Dom Wydawniczy REBIS, Poznań 2004, s. 101.

¹⁵ A. Nowak, K. Krejtz, Internet z perspektywy nauk społecznych, [w:] D. Batorski, M. Marody, A. Nowak (red.), Społeczna przestrzeń Internetu, Wydawnictwo Szkoły Wyższej Psychologii Społecznej "Academica", Warszawa 2006, s. 113–132.

¹⁶ B. Aouil, *Poradnictwo i wsparcie psychologiczne online. Przegląd i sugestie*, [w:] M. Piorunek (red.), *Poradnictwo. Kolejne przybliżenia*, Wyd. Adam Marszałek, Toruń 2011, s. 323–330.

to higher-order needs. And this is the role of the Internet that we should strive for.

The Internet acting as a global network, characterized by openness and unlimited contact, increases the probability of obtaining useful and necessary information and effective support, even accidentally and unintentionally. For example, by coming across blogs and forums of parents of children with disabilities. quite by accident, because it connects routes between different servers¹⁷. The social definition of the Internet draws attention to the fact that it is the most important carrier of civilizational change in the modern world. The Internet, which is a new, multimedia way of communication between people and institutions and a new society existing in the virtual space, has helped parents of disabled children find a way to show themselves and be present, something that traditional society did not always allow them to do. The Internet makes it easier to meet many needs, including the need for social support, which, if not met, gives an individual a feeling of loneliness in a difficult life situation. They emphasize that the ability to satisfy many needs allows us to treat the Internet as a society, and the generations satisfying their needs in this circle as an e-generation, because in online interactions, people look for much more than just contact. As in every society, there is a multi-layered game for social goods. They also draw attention to the group of people who run blogs, for whom they provide an opportunity to confide in their problems and share their thoughts. Attributing this feature to people under 16 years of age, they point out that this is a generation of people who are just learning to communicate their emotions and talk about problems with other people, but the same function is performed by blogs for parents of disabled children, who often do not find people with whom they could talk about problems. Hence, the therapeutic function of blogs should be supported.

Summary

Kościelska (2000), describing the situation of a parent of a child with a disability, writes about a life-disorganizing storm of fears, sadness, misunderstanding, loss, hostility and mourning permeated with various

¹⁷ J. Zielińska, Internet a niepełnosprawność, Wydawnictwo Naukowe UP, Kraków 2020, s. 46.

forms of multicolored love that they experience. Describes problems of family members and conducts interviews. He writes about identity crises. They can be overcome by obtaining support on the Internet, including creating a new identity in the virtual world, where it will be limited by the amount of information that the parents of a child with a disability control. This is very helpful for people who had to change their fear of having a child with a disability into an active attitude, effective rehabilitation and seeking help. By rationally approaching the fear of wasting the child's development opportunities, they must overcome the fear of the future every day¹⁸. Kościelska (2000) states that the medicine that heals wounds is social support, as well as contacts between parents. As something particularly valuable in confronting mutual problems, he mentions the most important needs of the family, such as social acceptance and a good place in the system of social care, educational and rehabilitation services, the latest, true, complete and comprehensive information regarding, among others, specialized facilities, associations, the nature of the disease and its rehabilitation, technical improvements, as well as the ordinary human need, a sense of belonging to a community, a group that gives a sense of bond and support, as well as modeling patterns of constructive coping with the situation¹⁹.

The lack of sufficient institutional support for families of children with disabilities entails, among other things, the need to activate and use family support networks, including the Internet²⁰. The Internet provides parents of disabled children with many types of support, from emotional, through evaluative, instrumental, informational, and even spiritual. Creating blogs, internet forums, searching for associations and foundations, as well as access to the latest rehabilitation achievements make it easier for families to overcome everyday difficulties. The problem of disability manifests itself in family life in two ways: firstly, the family as a social environment provides a disabled person with mental, physical and emotional support. On the other hand, the family, as the environment closest to a disabled person, experiences direct consequences of the dysfunction of one of its members²¹.

¹⁸ M. Kościelska, *Oblicza upośledzenia*, PWN, Warszawa 2000, s. 41–56.

¹⁹ Ibidem, s. 77.

²⁰ J. Zielińska, Internet a niepełnosprawność. Wybrane zagadnienia, Wyd. Naukowe UP, Kraków 2022, s. 17–25.

²¹ M. Ogryzko-Wiewiórkowska, Społeczna kondycja polskiej rodziny zmagającej się z niepełnosprawnością, [w:] B. Skrętowicz, M. Komorska (red.), Osoby niepełnosprawne w społeczeństwie polskim okresu transformacji, Lublin 2008, s. 101.

Therefore, a family with a disabled child needs comprehensive help in coping with a difficult situation such as the child's disability or even the threat of abnormal development. The presented research is an attempt to address this topic, of course to a rather limited extent, because the Internet is a space for supporting families of children with disabilities. This may be supplemented by forms of support described in the literature on the subject, with specific practical solutions and examples, such as: discussion groups, forums, blogs, websites, services of online specialists, or self-help groups used by parents of children with disabilities.

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