



Nethnographic Research Report on Families with Members with Disabilities in Social Media and Facebook

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Abstract

Article presents ethnographic qualitative research report partially based on the research completed in 2017 as thesis at the Chair of Disability Studies, Faculty of Education Sciences, Nicolaus Copernicus University in Poland. The research was conducted within 4 online open groups, organizational cultures of families with children, youth or adults with disabilities who are participating in social media in Poland. The primary focus of the research was the law and legal issues' perception by families. However, in this paper we refer to wider aspects of general online activities undertaken by the members of researched 4 groups, that in fact form online organizational disability cultures. Presented results of analysis contain categories as: basic cultural artifacts (material and symbolic), values of 4 analyzed groups and underlying assumptions, according to the model of organizational culture by Edgar H. Schein (2010). Furthermore we discuss the general activities of participants in the context of the core research topic that was law and legal aspects of public online discussions. The main research question was formulated as follows: how families (from 4 organizational cultures online) with members with disabilities are active on social media in the context of the law and legal issues? Collected qualitative data was elaborated on the ground of the organizational culture model according to 3 levels of organizational culture indicated by Schein (2010) as: 1. artifacts, 2. espoused beliefs and values and 3. cultural underlying assumptions.

Keywords: Internet, organizational culture, ethnographic research, legal issues, social media.

Introduction

Families with members with disabilities in Poland openly verbalize needs, expectations or demands on social media, blogs, and websites. Such activities are becoming increasingly the subject of scientific works in Poland. There are still present problems of improper resolutions of the matters related to the adaptation of laws and regulations to the needs of people with disabilities and their families. Caregivers call on social networks for greater support from the state or local government. The main problem verbalized by parents of children, youth and adults with various disabilities is related to numerous signs of discrimination the family members notice also in the legal sphere. This issue was seriously raised in 2002 at the European Congress of Persons with Disabilities. According to the opinion of the participants of this congress, legal changes are associated with changes in social attitudes, vocational activation of adults with disabilities or widening of their autonomy (Cytowska, 2011). Polish families raising or living with members with disabilities increasingly and courageously express their opposition to inadequate government attitudes and lack of support from them. Gotowicka (2004) wrote about it in early 00s. : "in the last few years the approach to the persons with disabilities has changed in Poland. They are no longer invisible citizens. They demand equal opportunities and rights. However, Polish legal solutions intended to serve these people are still far from perfect."(p. 193). About political activities of Polish families with children with disabilities fighting for equal rights wrote Żyta & Ćwirynkało (2015). The authors analyzed the support for families that is received from associations of parents.

Gotowicka (2004) points to the need not only for legislative changes, but also for raising public awareness of the fact that "the persons with disabilities have the right to protection against discrimination and to hold their rights on an equal basis" (p. 194). Zych (2007) indicates the important role of information support as a means of preventing legal discrimination against people with disabilities and their families. This support should be based primarily on the provision of legal advice. The issues of the needs, possibilities and

general social and cultural situations of people experiencing limitations of functioning, including people with disabilities and their families, are an important element of the research of Polish academics, social scientists. About these issues write: Frąckiewicz (2008), Gajdzica (2009, 2013), Zakrzewska-Manterys (2010), Borowska-Beszta, (2012, 2013), Pyżalski (2012), Chrzanowska (2015), Zakrzewska-Manterys & Niedbalski (2016), Chodkowska (2016), Bartnikowska, Borowska-Beszta & Stochmiątek (2015), et al. Furthermore in media coverage in Poland since about 90s. can be noticed an increased interest in the issues of legal exclusion of persons with disabilities. Polish press and social media monitor since 2013 the protests in public places of groups of parents with children, adolescents and adults with disabilities.

Review of Literature

Organizational culture

According to Kostera (2005) organization is a *type of culture*. Whereas *organizational culture* is a set of artifacts, values, goals, norms and cultural assumptions (Schein, 2010). Wiernek (2000) and Róg (2007) also indicate that the organization's culture is a set of concepts such as: norms, values, attitudes, and beliefs common to members of the organization, that were created to explain a great deal of what is happening in organizations. The basic elements of organizational culture according Wojtowicz (2004) include: "symbols, ways of communicating, rituals, myths and taboos" (p. 160). About the unique character of organizational culture writes Zbiegień-Maciąg (2005). The author writes that most researchers, regardless of their orientation, agree in the following statements that: first: culture in organization exists, second: each culture is unique, third: culture is a kind of building blocks of desirable organizational behaviors, internal identity and external image (p. 14).

Wojtowicz (2004) writes that "the Schein's model is of particular value in the research of organizational culture, as it shows the relationships between the different levels of organizational culture, while stressing the difficulty of their detailed analysis due to the limited perception of all components of this phenomenon"(p. 168). The basic criteria defining the components of model created by Schein (2010) are ease of observation and degree of awareness. These criteria affect the division of organizational culture into three levels, that are: 1. artifacts, 2. espoused beliefs and values, and 3. basic underlying assumptions (p. 24). Schein (2010) emphasizes that cultural assumptions that make up the third level of organizational culture are extremely difficult to change, and this implies a lack of awareness of mechanisms inside them (p. 28).

Families Online

Lubański (2004) writes, that "Internet technology, is destroying the current media model of information, is approaching the environment and is creating new kinds of bonds, beneficial for people with disabilities (p.24). The Polish families are currently more actively organizing themselves in advocates groups participating in social media. They share, discuss and criticize aspects of everyday living, including social policies, systems of support, law and legal acts. As we mentioned before families became actively organized in public spaces and online since about 2013. For 4 years they gradually share more courageously own ideas, critics, organize protests against systems of support. In 2016-2017 while massive feminist movements protest there were present in Polish mainstream and social media important public debates related to problems of *eugenic abortion* and *pro-life* concepts including generational and procreative families, living with members with disabilities (Borowska-Beszta, 2017). An important topic relating to voices of families was and still is the associated with the law, legal

acts and human rights. Families engage in organized protests in public spaces as well as online, that purpose is associated with the need of changing of the current law. These groups of people, called by Brown (2002), Borowska-Beszta (2012, 2013, 2014) *disability cultures* strived and strive until now for social changes. Presently generational and procreative families in Poland create a variety of associations and organizations, that are active online with a aim of helping the members of *disability cultures*. An interesting sphere, that has gained huge popularity as medium of communication within discussed groups of families is the internet and social media.

The basic issue associated with the starting online groups by the families having members with disabilities is the desire to change and the need to obtain support. Opinions of the parents of children with intellectual disabilities on the assistance provided to the family collected and analyzed Kazanowski and Byra (2004). Results of their research indicate, that the most important issue for the participants are forms of *financial support*. Other areas of assistance have less importance for parents. For example, the authors notice that social activity and taking initiatives to improve own situation of families largely isn't located in the center of interests of discussed families. According to Kwaśniewska and Wojnarska (2004) 80% of parents is not interested in participating in associations or self-help groups developed by parents of persons with disabilities (p. 145-146). Therefore, the authors are putting the following thesis: "lack of basic expectations from the institutions or organizations may arise from *insufficient information system* on available forms of assistance, as well as the lack of motivation after unsatisfactory experience in earlier periods of life" (p. 147).

Masłyk and Migaczewska (2014) made an interesting analysis and characteristics of general Polish population with disabilities who used in 2013 the Internet. "The project was titled *Social Diagnosis. The conditions and quality of life of Poles* and was undertaken in 2013 and 2014. The survey was based on a sample of 26,307 individuals of the respondents, 11% were disabled." (p. 29). In the results section the authors write: "first, among the disabled network users are dominated by pensioners (30.6%) and active people professionally (30,2%). They also include a vast majority of the disabled students and students (among whom 7.2% were internet users and only 0.2% not using). Similar dependencies as regards the last two categories, they are among the active Internet users - mainly network users people working and learning. Secondly, disabled Internet users are most often urban dwellers (78.7%). Third, the average age of disabled Internet users oscillates around 47 years old. Non-disabled network users are on average 10 years younger"(p.37). The author continues that "unfortunately, there are very few of them - the Internet uses just every third disabled person" (p. 37).

Numerous Polish academics are publishing reports of the advantages and disadvantages of using the Internet by people with disabilities and intellectual disabilities. About disadvantages and cyber bullying as general phenomena writes Pyżalski (2012). Issues of using the Internet by students with intellectual disabilities analyzes Plichta (2013). Risk of hazard of using the Internet by students with special needs analyze Plichta and Pyżalski (2016). The advantages of using the Internet by persons with disabilities analyzes Grześkowiak (2010) and Smoczyńska (2010). Grześkowiak (2010) indicates following advantages in following areas as: "communication information, employment, e-commerce as teleshopping and banking services, education, costs of living that are decreased" (p. 15). Smoczyńska (2010) analyzes the social and virtual activities of adults with disabilities. The author shows that the diversity of the social environment (virtual and real) can largely affect maintaining satisfactory relationships with other people and to effectively deal with some problems related to disability. The author writes: "people who use the Internet, and in

particular these, who are the participants in the virtual communities, are assessing their life better than those not participating at all in diverse social environment called the Internet"(p. 71).

Polish adults of both sexes with various developmental disabilities (including intellectual disabilities of mild and moderate levels) jointly with their parents are currently regular participants of various social media networks including Facebook. There is for example Facebook fun-page developed by Polish female poet with Down syndrome (and her family) tit. *Miss Mary of Poems* (Borowska-Beszta 2015). Borowska-Beszta (2013) conducted the ethnographic research in 2007-2009/10 and analyzed the lifestyles of 50 young Polish adults with intellectual and developmental disabilities and indicated online activities of adults with mild and moderate intellectual disabilities as members of *Our Class* a Polish website grounded thematically in schools and education. Such activities gave the participants a lot of enjoyment and social connections with former or present school colleagues, friends and teachers. The interesting remark the author made observing personal profiles on *Our Class* (Nasza Klasa) of adults with intellectual disabilities, that there was no single adult who would openly mention and place as well as the full name own attended or graduated school (special school, special vocational school etc.). The names of *special schools* as the stigma pattern, remained the taboo area. However, in many cases participants of the ethnographic research, adults with disabilities had many former teachers in the circles of invited friends.

Research Design

Reported qualitative research was grounded in constructivist paradigm after Denzin, Lincoln (2009), Jamielniak (2012a, 2012b), Kubinowski (2010), qualitative methodology according to Creswell (2009), Angrosino (2010), Silverman (2010), Flick (2010), Kvale (2011), Gibbs, (2011) and nethnographic method according to Kozinets (2012). The qualitative research was carried online in Poland since 2016-2017 online within 4 Polish online groups developed by members of generational families of persons with disabilities.

The main research question was formulated as following:

- how families (from 4 organizational cultures online) with members with disabilities are active on social media in the context of the law and legal issues?

The detailed research questions were specified as:

- what attitudes express the families of people with disability towards an existing law and legal acts?
- what artifacts, espoused beliefs and values and cultural assumptions can be distinguished within researched groups?

Method

According to Creswell (2009), Borowska-Beszta (2005, 2013), Flick (2010), Silverman (2010), Kubinowski (2010), Angrosino (2010), Jamielniak (2012a, 2012b) and Kozinets (2012) qualitative researchers indicate, that the basis for the project is to define topics, areas and precise research questions. The research project started with general issues as:

- *First*: defining the main theme as law and attitudes towards by the families of people with disabilities.
- *Second*: designing the main and detailed research questions, that formed the ground of the analytical form.

- *Third:* identifying and selecting the scene and purposive samples as online groups.
- *Fourth:* observing selected online communities and collecting the data for 8 months. The collection was done by systematizing research material according to the elements of organizational culture.
- *Fifth:* analyzing of collected research material, interpretation of the results.

Purposive Sample

Initial analysis of accessible Polish community portals and internet forums showed, that within the Internet websites exists possibility to find many various places with families having members with disabilities as participants. For the research purposes there were chosen 3 online forums and 1 Facebook group listed below with encryption assumptions. All selected Internet forums have received codes as Forum A, B, C, and the Facebook group has been marked with A.

- **Forum A** – forum of parents of children/youth/adults with Down syndrome: 4000 members
- **Forum B** - forum of mothers bringing up children/youth/adults with disabilities: 5000 members
- **Forum C** - forum of families with people with congenital defects: 1000 members
- **Facebook Group A** - a group on Facebook website of parents of children/youth/adults with disabilities: 4000 members

Data Collection

Observation online

The observations and collection of the field notes (as comments, expressions, voices), from 4 groups (3 forums on social media and 1 Facebook group) were undertaken for 8 months (since October 2016 – until May 2017). Internet non-invasive observation allowed for reaching target groups, with which the direct contact can be hampered. The netnographic observation according to Kozinets (2012) has passive character, that is called peripheral. However, according to the author the conduct of research in the Internet environment limits the possibility of observing psychological reactions of the participants. Choice of observation as techniques was associated with a factors we precise below. Important was enhancing the possibility of the access to the information from families of people with disabilities without interrupting and interfering into their privacy. There were chosen the roles of the researcher "standing on the sidelines" that is observing without the active participation within the community.

Goals of observations:

- First observational goal was to obtain a deepest attainment to existing artifacts, materials, created by the members of groups
- The other goal was to reach real values, beliefs and feelings of families of people with disabilities, expressed spontaneously as their reactions to changes in the legal system that creates
- Third goal of the observations was to analyze the written interactions between members of individual groups.
- The analyzed patterns concerning the activity of families of people with disabilities towards Polish provisions of the law were concentrated around years 2015-2017. This

decision was made according to intense period of legislative changes in Poland related to life of people with disabilities and their families.

Ethics of Data Collection

- The names of 3 forums and 1 Facebook group were anonymized and coded as Forums A, B, C, and Facebook Group A
- The observations were undertaken only in public open forums and groups so personal consent wasn't needed.
- The optimal and accepted was non-participant and passive observation as the research technique

Data analysis

The basic used tool during observations was the *observation form*. All analysis of collected data were based on the observation form prepared according to 3 levels of the organizational culture model by Schein (2010).

Table 1. *Observation form*

Organizational culture levels
1. <i>Legal artifacts:</i> <ul style="list-style-type: none">▪ What specific patterns of attitude towards law exist in communication of members of families with people with disabilities?▪ What visual and textual artifacts represent groups identification (photos, texts)?
2. <i>Espoused beliefs and values:</i> <ul style="list-style-type: none">▪ What are the values and beliefs of the members of analyzed groups?▪ How do members of the group refer to the legal issues in the Polish legal system?▪ What norms are the basis for the formation of values within groups?
3. <i>Cultural assumptions:</i> <ul style="list-style-type: none">▪ What are the sets of beliefs and assumptions that underpin the group members?▪ How do group members perceive <i>other</i> people outside of the groups ?▪ How does a group perceive itself ? (e.g. as being dominant or trying to get <i>out of the niche</i>)▪ How are the members of the group oriented towards the past, the present or the future?

Analytical Steps

- Field notes collection.
- Coding, categorization, comparison. Selecting, tidying up statements of comments made by people and own notes according to research questions.
- Abstraction. Was tied with separation of categories in the more general and abstract groups related to three levels of organizational culture, according to Schein (2010).
- Internal generalization. The sets of categories tidied up of the category in order to develop certain internal generalizations.
- Formulating concepts and interpretation. The last stage of action associated with analysis and interpretation of the research material.

Results

Results of the ethnographic research are presented according to the 3 levels of the organizational culture model by Schein (2010). The author writes that, artifacts are constituting the basis of functioning of organizational cultures. They are open, easily noticed elements without going deep into the structure of action of the given community. In the

context of families of people with disability as the most interesting we recognize these artifacts that are connected with the *self-image*, *communication*, and *interactions* between members of specific 4 online groups.

Artifacts

In case of artifacts we notice interesting areas in terms of analysis of the organizational culture. Artifacts are of special importance in the comprehensive insight at activity of families of people with disabilities. However, they do not refer directly to sphere of provisions of the law neither the way participants of forums and group are taking a stance on these provisions. Research indicates, that artifacts are playing important role as the source of knowledge about selves, general relationships between members of groups, forming the specific organizational cultures. The artifacts associated with the sphere of the communication about the legal issues, have a great importance on account of peculiar character of virtual groups. Communications contents hidden within all comments constitute data are concerning two consecutive levels of the organizational culture according to artifacts: material (visual, verbal) and symbolical (visual, verbal)

Photographs: Are such artifacts, including ID badges and photographs of members of analyzed 4 groups that are easily recognizable elements of the organizational cultures. Extremely, photographs with members of the families are placing as the additional components of the identification. A lot for users are attaching their own photographs to the ID badge, that develops visually portals and forums. In case of families with children, youth or adults with disabilities, very often are shared photographs of one's children. Parents are sharing with other group members parts of their private lives that focus on children or other members with disabilities. Photographs are sometimes depictions of smiling children of various age, that are introduced alone or in the company of the parents or siblings. Showing the identification such a way can be related in our opinion to the *desire for joint surviving experiences along with members of virtual community*. Parents forming a union groups on the Internet are creating peculiar disability cultures, for whom the shared *fight* against legal and other oppressions constitutes the core pattern named as: *for the good of children*. Photographs as the basic components of identification are a crucial elements of the organizational cultures in the sphere of material and visual artifacts.

Mottos, Aphorisms, Quotations: Aphorisms, quotations and other types of texts are the symbolic, behavioral artifacts that let the users of portals to enrich their statements. Members of Internet groups are using motivational quotations from various sources in the objective of strengthening of the statement and metaphorical handing over contents important for oneself. These texts are becoming supplementing the statement or appear as the addition under the main meaning of the comment. Some portals enable users to put plots accompanying their statements. Aphorisms and quotations refer to such universal notions as: *good, beauty or love*. These values were significant for all members of analyzed 4 organizational cultures of families active online.

Values

Help: By pointing at common standards and cultural importance are being created common spaces to the organizational cultures of the group of family members. Furthermore, families are pointing online for the help and the interpersonal cooperation as to important values in their lives. The aspect of the help is turning up repeatedly in communication between people creating virtual communities. The help as expressed quality often shows the

broad dimension by indicating that even difficult practical or personal experiences can bring positive effects.

Openness and critical opinions of law: was also noticed during analysis of collected data. Parents within 4 internet forums are giving very often their critical opinions about valid provisions of the law. Members of 4 groups refer negatively to obligatory legal norms in the Polish legal system. Discussions concentrated around the subject matter of amendments to legal acts or creating new regulations are confirming it. The disagreement with restricting laws towards families of people with disability constitutes the crucial element of the organizational culture of groups. Families are paying attention to the lack of the comprehensive look ruling to problems with that people with disability are contending. In our opinion the data that is referred for perceiving provisions of the law by families has a considerable value for people with disability.

Openness in discussions: means that 4 groups of families are not closed in space of own opinions, but they are open on the opinions shared by the other members of a virtual community. Openness characterizes their aspiration to that each of participants of discussion would be treated without the limits by the group. Members of 4 groups of families with children, adolescents or adults with disabilities are open to discussion as well as willing to hear out the others' opinions on themes, associated with legislative solutions and possibilities.

Cultural Assumptions

After analysis we indicate the 5 cultural assumptions lying deeply on the ground of 4 analyzed cultural online scenes and groups. There are: *legal anxieties, legal hurts, legal preventions, sense of togetherness, advocacy and subsidiarity.*

Legal anxieties: Assumptions constituting the basis of organizational functioning of 4 online groups refer in great measure to anxieties, of the fears associated with the future and verbalized by members. The time for families is becoming a crucial element of the everyday life. Negative experience, experiences from the past, fighting about worth living here and now, for oneself and closest, are finding their reflection in comments placed on community portals through of families of people with disability. We would like however to concentrate above all on the *future*, because issues associated with fear and anxieties for the future most often turn up at the context of perceiving provisions of the law by families with people with disabilities. Parents are emphasizing that the legislative instability is heightening a feeling of being lost in the anxieties, are associated with the more distant life. Families of people with disability on the Internet are sharing their fears concerning changes in the provisions of the law, that they perceive as worsening their situation in life. *Inequality* is an often expressed pattern in the system of families' opinions.

Legal hurts: Next cultural assumption holding 4 analyzed groups of families is sense and feeling of hurt. Parents are showing views in certain areas literally and directly, however these negative emotions stay in many cases in the latent sphere. Analyzed families of 4 groups of people in opposition towards in improper legal terminations view, are joining the comments concerning the *social inequity*. People are presenting the negative vision of legislative organs. They express statements that they don't receive enough support from authorities. Many times the participants of 4 groups share also opinions on being totally ignored by authorities and legal system. Parents actively sharing their opinion on community portals think, that they are wronged and are becoming a *scapegoats*, that it is they are becoming main culprits of failures in life of their children.

Legal preventions: Parents of children, adolescents and adults with disabilities are emphasizing that existing laws and regulations are *preventing* them from correct functioning in the society. Parents would like to work, would like to live without fear against the future and financed protecting their children. Members of 4 groups are expressing the opinion that their effort aren't noticed and appreciated through others. *Families think that in the public sphere they are being spotted as the ones which are unproductive.* Families of people with disability are spotting Polish provisions of the law as worse than the ones to which they are applying in other countries. Acting people in frames of 4 groups analyzed are pointing at positive legal solutions functioning in countries of Western Europe in order to pay attention to the fact that, needs of people with disability and their families can to be included into the right way in normative acts.

Sense of togetherness: With consecutive element of cultural assumptions constituting the base of the 4 online organizational cultures of families there is a sense of togetherness. Through a detailed analysis of placed comments on community portals, forums and blogs we noticed that a special bonds were joining people, creating the given Internet communities. 4 groups of analyzed families who have members with disabilities are sensing the existence of the unity between them through shared experience. They are creating online communities as *online cultures* in fact the cultures of beliefs, norms, values, practices and desires. Within provisions of the law communities move close to current functioning standard solutions and to possible forms of changes in order to streamline the system of the support and the help.

Advocacy: Communities developed within 4 *disability online cultures* have besides the desire for taking cohesive action about local as well as nationwide character. Parents involved in creating Internet communities are motivating the high activity to themselves to the purpose of the change of the own their situation in life. They are writing moreover about what was already pretended to achieve. Joint achievements, successes are a crucial element uniting community of families of people with disabilities. Members of studied 4 groups are repeatedly emphasizing that positive changes, associated with provisions of the law, result above all from their activity and activity to the purpose of the vital improvement the situation of persons with disabilities. A feeling of being lost and the lack on the legal, institutional support cause that parents are looking for help from other people with similar practical experience of disabilities in family.

Subsidiarity: A concern and an interest of others are the last element associated with cultural assumptions generated from the data collected from 4 online groups of families. We perceive these elements in many statements of members of 4 Internet communities of families of people with disabilities. In our opinion issues of the subsidiarity constitute the important component shaping the organizational cultures of these groups. This issues were made aware, but simultaneously very often was turning up in hidden (*tacit*) area. Interest in matters and needs of *the other* is an important issue, very often expressed by members of studied families. In the context of provisions of the law, members of 4 virtual communities we analyzed, are highlighting that positive changes of the legal system can have a positive effect on a change of social attitudes towards persons with disabilities and their families.

Conclusion

In Polish social and cultural realities the problems of everyday lives people with disabilities and their families seem to be by a certain part of society however not always properly noticed. Results of referred nethnographic research report show similar situation. 4 groups of researched online families are feeling left alone with their problems by the system of support and legal solutions. We noticed also verbalized by participants of 4 online

disability organizational cultures, areas of *legal oppression, discrimination, stigmatization, exclusion* in the Polish dominant culture. The difficulties faced constantly by 4 groups of families with people with disabilities, are related to many different areas as *education, employment, social activities, health care or income*.

We must highlight, that social media and Internet have an important communication functions – is the area that creates community and unique relationships within 4 groups being analyzed (3 forums and 1 Facebook group). Analysis of collected data let us for drawing a few most important conclusions related to current legal acts and law and its' perceptions by analyzed 4 disability online cultures.

- *First:* The opposition to the legal system by the groups of families being analyzed is pointing at the fact that members of 4 groups are deeply conscious of their social situation and are aspiring to her improvement.
- *Second:* Developed social bonds within groups and community are the important part of the cultural assumptions of analyzed 4 organizational cultures.
- *Third:* Members of 4 groups of families are spotting provisions of the law as wrong and maladjusted to desires and needs of persons with disabilities. Therefore are uniting into groups in the Internet space in purpose of joint debate about possible forms of changes of the oppressing system of law. Also the fact that by forming the unofficial quasi task-forces on the Internet, families of people with disability have a chance for sharing own knowledge and unique experiences.
- *Forth:* Provisions of the law constitute the important source of creating online the organizational cultures of families with members with disabilities. The families are engaging in the activity in social media and Facebook related to public debates in reality on legislative changes. Online activities allow the members to form reinforce social and cultural bonds between the other families with members with disabilities and to develop *online disability organizational cultures*.

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