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The Category of Disability in the Public Sphere

Thesis Summary for the purpose of obtaining academic degree PhD in Sociology

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Problem statement

The category of disability today is no longer a peripheral category of the social sciences. On the contrary, having come a long way in the academic debate between the sociology of body and disability studies, this category becomes central for understanding modern sociality. We are witnessing a new movement for the mobilization of individual and collective narratives, which initiate the recognition of disability experiences as significant and visible in the public sphere.

Scientific interest in the category today is inspired by the need to explain and criticize the existing models of disability interpretations both in the academic field and in the broader public discourse. Modern research emphasizes that the appeal to the category of disability, even in everyday contexts, obeys theoretically loaded constructs[1]. First of all, these are the ideas about the norm and "typicality", the connection of "markers" of disability (chair, cane, speech synthesizer) to social attitudes and hierarchies. In addition, researchers insist on the transformation of the nature of the public discussion, within the framework of which social interpretations of disability are formed and the personal stories of people with disabilities themselves become visible[2].

The models of disability understanding that have developed in academic and public discourse are criticized following the modern theories of mediatization of the public sphere[3] and the transformation of the "visibility-related public sphere conditions"[4]. Another direction is the revision of the structural and ideological changes in modern concepts of citizenship and identity[5]. In particular, this is especially highlighted in the multiple spaces of disability and sexuality narratives in modern Russian media and social networks[6]. Social, medical, and legal definitions of the category are constantly expanding, and with them, the contexts of everyday interactions, institutional practices, and ways of public perception are changing.

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[1] Grue J. Disability and Discourse Analysis. London: Routledge, 2015. P. 27-29

[2] Trevisan F. Disability Rights Advocacy Online: Voice, Empowerment and Global Connectivity. New York: Routledge, 2017; Ellis K., Kent M. Disability and Social Media: Global Perspectives. London, Routledge, 2016; Ellcessor E., Kirkpatrick B. Disability Media Studies, NYU Press, 2016.

[3] Thompson J. B. Shifting Boundaries of Public and Private Life// Theory, Culture & Society. 2011, V. 28 (4), 49–70; Couldry N. Mediatization or mediation? Alternative understandings of the emergent space of digital storytelling// New media & society, 2008, 10 (3), pp. 373-391

[4] Dahlberg L. Visibility and the Public Sphere: A Normative Conceptualisation// Javnost - The Public, 2018, 25:1-2. P.37.

[5] Giddens A. Modernity and Self Identity: self and society in the late modern age. Cambridge: Polity Press, 1991; Castells M. Communication Power. Oxford: Oxford University Press, 2009; Brubaker R., Cooper F. Beyond "identity"// Theory and Society 29, 2000, pp. 1–47.; Hermes J., Dahlgren P. Cultural studies and citizenship// European Journal of Cultural Studies, 2006, 9(3), pp. 259-265; Plummer K. Intimate citizenship: Private decisions and public dialogues. Seattle: University of Washington Press, 2003.

[6] Iarskaia-Smirnova E., Verbilovich V. "It's No Longer Taboo, is It?" Stories of Intimate Citizenship of People with Disabilities in Today's Russian Public Sphere// Sexuality & Culture 24, 2020, pp. 428–446.

The expansion of the semantic fields and models for understanding disability leads to the resources of discursive theories in the field of disability studies[7]. This approach allows us to explain how the category is filled with meanings "from above" in institutional definitions and classifications, and "from below", with the help of performative resources in the public sphere[8]: stories of persons with disabilities themselves in autobiography and art projects, grassroot initiatives, and NGO public campaigns. In this regard, it is crucial to revise the existing theoretical models of disability[9] and the grounds for problematization of the category, taking into account the structural changes in the concepts of identity, citizenship, and modern publicity.

The project of the dissertation research has developed as a long process of searching for analytical and methodological resources for the study of disability as a discursive phenomenon of the public sphere. This study proposes an integrative concept, which explains the ongoing global and local transformations in the social understanding of disability. We are interested in how the very nature of the discourse is changing and with it the boundaries and content of the category of disability. The research also explains how the experience of disability transforms the public sphere of action and speaking.

The key advantage of the study is a comprehensive view of these processes within the "structure" and "agency" dichotomy[10]. By sustainable social structures, we mean the models of disability understanding, social and speech conventions that designate the category at the institutional level. The "structurally transformative agency"[11] concept is used in this work, to identify empirically measurable individual choices that change social structure.

The mobilization of persons with disabilities' collective action which is contributing to the revision of social norms and practices in education[12], urban environment accessibility[13], and inclusiveness of digital narratives of disability[14], can serve as examples of the empirically measured agency. The history of the movement for the rights of people with disabilities and the

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[7] Corker M., French S. Disability discourse. Buckingham; Philadelphia, Pa.: Open University Press, 1999; Titchkosky T. Disability Studies: The Old and the New// The Canadian Journal of Sociology/ Cahiers Canadiens De Sociologie, 25(2), 2000, pp. 197-224; Grue J. Disability and Discourse Analysis. London: Routledge, 2015.

[8] Арендт X. Vita activa, или О деятельной жизни / Пер. с нем. и англ. В.В. Бибихина. СПб.: Алетейя, 2000; Butler J. Excitable Speech: A Politics of the Performative. N.Y.: Routledge, 1997.

[9] Grue J. Discourse analysis and disability: Some topics and issues. Discourse & Society, 2011, 22(5), 532–546.

[10] Giddens A. The Constitution of Society, Berkley, CA: University of California Press, 1984; Hays S. Structure and Agency and the Sticky Problem of Culture. Sociological Theory, 12(1), 1994, pp. 57-72; Connor S. Structure and agency: A debate for community development?// Community Development Journal, 2011, 46(S2), pp. 97-110.

[11] Hays S. Structure and Agency and the Sticky Problem of Culture// Sociological Theory, 12(1), 1994, pp. 57-72

[12] Развиваем инклюзию: «У роки доброты» для петербуржцев// Санкт-Петербургская ассоциация общественных объединений родителей детей-инвалидов, «ГАООРДИ». URL: https://gaoordi.ru/news/377/ Дата доступа: 15.02.2020

[13] Люди с инвалидностью проверили Владимир на доступность// АСИ. Регионы, 16.11.2015 URL: https://www.asi.org.ru/news/2015/11/16/lyudi-s-invalidnostyu-proverili-vladimir-na-dostupnost/ Дата доступа: 6.03.2020

[14] «Надо же, девочка с палочкой»: Как я живу с ревматоидным артритом// Wonderzine, Личный опыт. 30.10.2018 URL: https://www.wonderzine.com/wonderzine/health/personal/238777-rheumatoid-arthritis

accumulated experience of collective action in Western and post-Soviet countries, allows us to speak about the structural impulse for social transformations that have been observed in recent decades in Russia.

Specifically, the United Nations Convention on the Rights of Persons with Disabilities, adopted by a resolution of the General Assembly in December 2006[15], has become the main reference point to emphasize the international context of changes in the social and legal understanding of disability. After the entry into force of the Russian Federal Law No. 46-FZ, "On Ratification of the Convention on the Rights of Persons with Disabilities" in May 2012, not only the norms of law and social policy but also the norms of public discussion and ways of representing disability in the media[16] changed. Between 2010 and 2020, several state programs for the development of an accessible environment and urban infrastructure were adopted ("Accessible Environment 2011– 2025"[17]). Civil society organizations and communities of experts have lobbied for important social reforms. The concept of "inclusive education" was integrated into the Federal Law on Education[18] (2013), the Federal standard for Accompanied Employment[19] was approved (2018), and an active public discussion on reforming the system of residential institutions is underway[20].

The foundations of classical and modern theories of the public sphere, modern concepts of social identity and citizenship, and approaches to understand disability as a discursive construct, can be valuable and insightful resources to investigate the category of disability and create a typology of meanings attributed to it, in the modern Russian public sphere.

We assume that in the modern Russian public sphere, "traditional" and "new" representations of disability coexist, and it often leads to a clash of social values and norms. Public scandals are studied to analyze the collision of the warring models of disability understanding. The research problematizes the agency modes of persons with disabilities and their support networks in a situation of public scandal[21].

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[15] UN Convention on the Rights of Persons with Disabilities and Optional Protocol, UN 2006// URL: https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf Access date: 12.02.2020

[16] Маркина В.М. Политика репрезентации людей с синдромом Дауна в современной публичной сфере// Публичная сфера: теория, методология, кейс-стади. Ярская-Смирнова Е. Р., Романов П. В., Иконникова Н. К. и др. М.: ООО «Вариант», ЦСПГИ, 2013. С. 187-206

[17] Программа «Доступная среда»// URL: http://government.ru/en/docs/3344/ Дата доступа: 1.03.2020

[18] Ст. 2 п.27 Федерального закона РФ от 29.12.2012 № 273-ФЗ «Об образовании в Российской Федерации»// URL: http://xn--273--84d1f.xn--p1ai/zakonodatelstvo/federalnyy-zakon-ot-29-dekabrya-2012-g-no-273-fz-ob-obrazovanii-v-rf Дата доступа: 10.02.2020

[19] Приказ Министерства труда и социальной защиты Российской Федерации от 03.08.2018 № 518н «Об утверждении федерального государственного стандарта государственной услуги по организации сопровождения при содействии занятости инвалидов»// URL: http://publication.pravo.gov.ru/Document/View/0001201808220025 Дата доступа: 5.03.2020

[20] Клепикова А. А. 2019. Специальные интернаты для людей с инвалидностью в России: тотальность под вопросом// The Journal of Social Policy Studies, 17(3), С. 453-464.

[21] Вербилович О.Е. 2018. «Запрещенный прием»: инвалидность и публичный скандал в традиционных и интернет-медиа //Мониторинг общественного мнения: Экономические и социальные перемены. № 1. С. 253-266

Literature review

The historical and conceptual context of a sociological exploration of the category of disability can be conditionally divided into several stages. At the beginning of the 20th century, such categories as "deviation", "defect", "illness", and "patient" began to be actively discussed in the social sciences. Early appeals to the topic of disability did not directly raise the issue of conceptualizing the category, but classical scholarship pondered the conditions and consequences of the phenomenon. In the 1920s, G. Simmel wrote about barriers for blind people in urban environments, in which, under the influence of industrialization, visual communication is becoming more important[22].

In the 1920-80s, social theories and concepts were developed that subsequently became fundamental to the study of disability both in sociology and interdisciplinary studies of disability ("disability studies"). This evolution in social sciences in the 1950s was, above all, the legacy of structural functionalism and symbolic interactionism: the conceptualization of "the role of the patient" and "illness career model" by T. Parsons[23], the category of identity in the theories of J. G. Mead, G. Bloomer and their followers[24]. E. Goffman addressed the concept of a "defective body" and developed theories of stigma and "spoiled" identity[25]. In the 1960s, the works of S. Naga and I. Zola appeared, where the authors conceptualized disability as a flexible category, the content of which is formed in the interactions of a disabled person with his environment and society as a whole[26].

The category of "social minority"[27] and theories of social movements of persons with disabilities as carriers of a special collective identity began to play an important role in sociology[28]. This approach was inspired by the human rights movements and the active protests of people with

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[22] Simmel G. Sociology of the senses: Visual interaction. Introduction to the Science of Sociology, 1921, 356 – 361; Mauldin L., Fannon T. 2017. The Sociology of Deafness: A Literature Review of the Disciplinary History// Sociology Looking at Disability: What Did We Know and When Did We Know it. By S.E. Green and Sh.N.Barnartt (eds.). Research on Social Science and Disability. Volume 9. Emerald Group Publishing.

[23] Parsons T. 1951. The social system. New York; The Free Press.

[24] McCall G. J., Simmons, J. L. 1966. Identities and interactions. Free Press.

[25] Гофман И. Стигма: Заметки об управлении испорченной идентичностью/ пер. М.С. Добряковой// Социологический форум, 2001. URL: https://www.hse.ru/data/2011/11/15/1272895702/Goffman_stigma.pdf Дата доступа: 12.01.2020

[26] Nagi S. Z. 1965. Some conceptual issues in disability and rehabilitation// Sociology and Rehabilitation/ Sussman, M.B. (ed.). Washington, D.C.: American Sociological Association; Zola I.K. 1982. Missing Pieces: A Chronicle of Living with a Disability. Philadelphia: Temple University Press; Zola I.K. 1986. Depictions of Disability: Metaphor, Message and Medium in the Media. Social Science Journal. 22:5–17.

[27] Stroman D.F. The awakening minorities: the physically handicapped. University Press of America, 1982.

[28] Shapiro J. P. 1993. No Pity: People with Disabilities Forging a New Civil Rights Movement. Times Books; Winter J.A. The Development of the Disability Rights Movement as a Social Problem Solver//Disability Studies Quarterly. V. 23 (1), 2003. URL: https://dsq-sds.org/article/view/399/545. Access date: 08.01.2020.

disabilities in the United States in the 1980s, resulting in the signing of the Americans with Disabilities Act on July 26, 1990[29].

In many ways, it is the accumulated experience of the 1960s and 1980s social movements in the USA and Europe that determined the significance of the category of disability in the theory and methods of producing academic knowledge. In the 1990s, researchers from the USA and UK initiated a new round of critical reflection of the theoretical and methodological experience of sociology in disability studies (C. Barnes, M. Oliver, G. Mercer, T. Shakespeare, J. Morris, M. Priestley)[30]. In their work "Disability: A Sociological Phenomenon that Sociologists Disregard"[31], K. Barnes and M. Oliver insisted on the inclusion of the category of disability in the analytical apparatus of sociology along with such categories as class, gender, and race. Similar to S. Nagi and I. Zola research at the previous stage of the development of academic ideas on disability, M. Oliver, C. Barnes, and T. Shakespeare substantiated the need to overcome the framework of biomedical approaches and shift the focus of study towards economic, political, and sociocultural factors at the heart of the phenomenon.

The next essential step was to turn to the critical theory[32] and resources of feminist theories[33] to deconstruct forms of inequality and oppression, ways of representing disability in popular culture. H. Mikosha insisted on overcoming colonialism and postcolonialism in the study of disability[34]. The discursive turn in the social sciences opened up a space for research of the disability discourses in the public[35] and academic[36] fields. These studies criticize the existing models of disability understanding, which define the category through the dichotomy of "medical" and "social", the ideology of the struggle of minorities and "vulnerable" groups social protection.

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[29] Gold S.D. 2010. Americans with Disabilities Act. Marshall Cavendish.

[30] Morris J. 1993. Independent Lives? Community care and disabled people. Basingstoke: Macmillan; Shakespeare T. Cultural representation of disabled people: dustbins for disavowal? // Disability and Society. 1994. 19. P. 283-299; Barnes C., Mercer G. 1996. Exploring the Divide: illness and disability. Leeds: Disability Press; Oliver M., Barnes C. 1998. Disabled People and Social Policy: from exclusion to inclusion. Harlow: Longman; Priestley M. 1999. Disability Politics and Community Care. London: Jessica Kingsley.

[31] Barnes C., Oliver M. 1993. Disability: a sociological phenomenon ignored by sociologists. Leeds: University of Leeds.

[32] Meekosha H. 2006. What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic// Scandinavian Journal of Disability Research. 8: 2-3, pp. 161-176; Shildrick M. 2007. Dangerous discourses: Anxiety, desire, and disability// Studies in Gender and Sexuality, 8(3), pp. 221–244; Roets G., Goodley, D. 2008. Disability, Citizenship and Uncivilized Society: The Smooth and Nomadic Qualities of Self-Advocacy// Disability Studies Quarterly, 42(4). URL: https://dsq-sds.org/article/view/131/131 Access date: 08.01.2020.

[33] Garland-Thomson R. 2002. Integrating Disability, Transforming Feminist Theory// NWSA Journal. Vol. 14 (3), Feminist Disability Studies: 1-32

[34] Meekosha H. What the Hell are You? An Intercategorical Analysis of Race, Ethnicity, Gender and Disability in the Australian Body Politic// Scandinavian Journal of Disability Research, 2006. 8: 2-3, pp. 161-176

[35] Mitchell D.T., Snyder Sh.L. The Body and Physical Difference: Discourses of Disability. Ann Abor: University of Michigan Press, 1997.

[36] Titchkosky T. Disability Studies: The Old and the New// The Canadian Journal of Sociology/ Cahiers Canadiens De Sociologie, 25(2), 2000, pp. 197-224; Grue J. Disability and Discourse Analysis. London: Routledge, 2015.

Researchers insist on the need to conceptualize the discursive model of disability[37], which will allow to comprehensively explain both the ways of understanding disability that have already established themselves as dominant (the models described above) and competing definitions that are born as flexible personal constructs and collective narratives in the spaces of public self-presentation of persons with disabilities.

In Russian sociological thought, studies of the category of disability are usually associated with the object of interests of health care, social work, and policy. Several studies focus on the medical interpretation of the phenomenon in terms of rehabilitation of individuals and social groups[38]. These problems are elaborated in the research by T. A. Dobrovolskaya, N. D. Shabalina; S. I. Grigoriev, A. E. Ivanova, O.V. Novozhilova, T. M. Maleva, S.A. Vasin, A.V. Demyanova, A. L. Lukyanova.

Studies of disability as a social and discursive construct of the post-Soviet public sphere and neoliberal relations are presented in the works by P. Romanov and E. Iarskaia-Smirnova[39], S. Phillips[40], K. Froelich[41], M. Rasell[42], K. Hartbley[43], M. Tsekhanovich[44], and V. Markina[45], E. Nosenko-Stein and A. Kurlenkova[46]. Modern studies of disability and sexuality in the paradigm of intersectional analysis are presented in the works by D. Zavirsek[47], E.R. Iarskaia-Smirnova[48], A. Kondakov[49]. The studies of mental health issues and disability experience in the residential care institutions are presented in the projects by A. Klepikova[50].

[37] Grue J. 2011. Disability and discourse analysis: Some topics and issues// Discourse and Society 22(5). pp.1-15

[38] См. например, Инвалидность и социальное положение инвалидов в России / под ред. Т.М.Малевой. М.: Издательский дом "Дело" РАНХиГС, 2017; Демьянова А. В., Лукьянова А. Л. Влияние статуса инвалида на предложение труда в России// Прикладная эконометрика. 2016, т. 44, с. 50–74.

[39] Романов П. В., Ярская-Смирнова Е. Р. 2006. Политика инвалидности: Социальное гражданство инвалидов в современной России. Саратов: Изд-во «Научная книга».

[40] Phillips S. D. Disability and Mobile Citizenship in Postsocialist Ukraine. Bloomington: Indiana University Press, 2010.

[41] Fröhlich C. Civil society and the state intertwined: the case of disability NGOs in Russia// in: Social Movements in Post-Communist Europe and Russia. L.: Routledge, 2014.

[42] Rasell M., Iarskaia-Smirnova E. R. 2014. Conceptualising Disability in Eastern Europe and the Former Soviet Union, in: Disability in Eastern Europe and the Former Soviet Union. History, policy and everyday life / Ed. by E. R. Iarskaia-Smirnova, M. Rasell. NY, Abingdon: Routledge.

[43] Hartblay C. 2014. Welcome to Sergeichburg: Disability, Crip Performance, and the Comedy of Recognition in Russia// Journal of Social Policy Studies 12(1)pp.111-125.

[44] Цеханович М. Что мешает развитию социального партнерства в России? Сравнительные общественных организаций инвалидов// Социальная политика в современной России: реформы и повседневность/ Под ред. П. Романова и Е. Ярской-Смирновой. М.: ООО «Вариант», ЦСПГИ, 2008. С.368-389

[45] Маркина, В. М. Механизмы производства инаковости в дискурсе: теория и методология анализа (на примере одного кинотекста)// The Journal of Social Policy Studies, 13(1), 2015. С. 49-64.

[46] Обратная сторона Луны, или что мы не знаем об инвалидности: теория, репрезентации, практики: сб. статей / отв. ред: А.С.Курленкова, Е.Э.Носенко-Штейн. — М.: ООО «Издательство МБА», 2018.

[47] Zavirsek, D. Pictures and silences: memories of sexual abuse of disabled people. International Journal of Social Welfare, 2002, Vol. 11, Issue 4, p. 270-285

[48] Ярская-Смирнова Е. Стигма «инвалидной» сексуальности // В поисках сексуальности. Сборник статей / Под ред. Е. Здравомысловой и А. Темкиной. СПб: «Дмитрий Буланин», 2002.

[49] Kondakov A. Crip Kinship: A Political Strategy of People Who Were Deemed Contagious by the Shirtless Putin// Feminist Formations 30(1), 2018. pp.71-90.

[50] Клепикова А. Наверно я дурак: антропологический роман. СПб.: Издательство Европейского университета в Санкт-Петербурге, 2018.

Recent research illuminates the criticism of the concepts of disability following the reflection of the contradictory trends in the mediatization of social interactions[51] and the phenomenon of "digital divide"[52]. On the one hand, the personalization of content and the participatory nature of social media, professional journalistic and fundraising online media projects expand the structural possibilities for the manifestation of agency and disability experience. On the other hand, structural inequalities persist in access to technology, communication methods and formats of expression. Foreign researchers study narratives of disability in social media and fundraising campaigns[53], the problems of access to digital platforms for people with different types of disabilities[54], the construction of representations of disability in the context of studying new media technologies and modern audience research[55]. S. Oats suggests paying attention to the formats of digital activism[56] of parents of children with disabilities in Russia.

Taking into account current research trends, the dissertation research focuses on understanding disability from the point of view of discourse theories. This approach makes it possible to revise the existing models of disability understanding concerning the new challenges associated with the expanding boundaries of the category interpretation in public and scientific discourses, as well as with the development of mediatized practices of representing disability in the public sphere.

Research question

How is the category of disability constructed in the public sphere?

Research aim

To develop an integrative concept for studying the category of disability as a discursive construct and agency mode in the public sphere.

Research objectives

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[51] Couldry N. Mediatization or mediation? Alternative understandings of the emergent space of digital storytelling. New media & society, 2008, 10 (3), pp. 373-391.

[52] Ragnedda M., Muschert, G.W. Theorizing Digital Divides (1st ed.). Routledge, 2017

[53] Trevisan F. Disability Rights Advocacy Online: Voice, Empowerment and Global Connectivity. New York: Routledge, 2017.

[54] Ellis K., Kent M. Disability and Social Media: Global Perspectives. London, Routledge, 2016.

[55] Ellcessor E., Kirkpatrick B. Disability Media Studies. NYU Press, 2016.

[56] Oates S. Parents and Patients. Online Health and Fairness Campaigns in Russia// in Revolution Stalled: The Political Limits of the Internet in the Post-Soviet Sphere by S. Oates. Oxford University Press, 2013.

1. To reveal and evaluate the heuristic resources and limitations of classical and modern theories for the sociological study of disability in the context of recent transformations of the public sphere.

2. To conceptualize the category of disability based on the interpretation of the types of discourse conventions on disability issues in the Russian public sphere of recent decades. The conventions are studied based on the results of expert interviews and analysis of secondary data.

3. To describe and explain the ways disability narratives emerge in the mediatized public sphere based on the study of social media and autobiographical projects. To explore the potential to redefine the private-public dichotomy in the manifestations of agency in the disability narratives.

4. To explore the transformation of the category of disability based on the study of the dynamics of scandal as a discursive event in the mediatized public sphere. To conduct the analysis of scandals on disability issues in the Russian mass media in recent decades.

5. To compile a repertoire of audiences' reactions and describe the ways the most active agents of the discussion about disability mobilize in the dynamics of a public scandal.

Methodology

The *theoretical object* of the dissertation research is the category of disability and the structural characteristics of the public sphere. We rely on discursive theories, according to which disability is understood as a construct of existing social and linguistic conventions[57]. We assume that the strengthening and (or) revision of these conventions are possible in the public sphere, with its potential for rational-critical discussion[58] and performative action[59]. The potential and limitations of modern "mediatized" publicity are taken into account[60].

The *empirical object* of the research includes personal narratives, public discussions, and situations of public scandals around disability in the Russian public sphere in recent decades (2000 - 2020). This period includes not only significant social and technological changes in the public

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[57] Corker M., French S. Disability discourse. Buckingham; Philadelphia, Pa.: Open University Press.; Grue J. 2015. Disability and Discourse Analysis. London: Routledge, 1999.

[58] Хабермас Ю. Структурное изменение публичной сферы: Исследования относительно категории буржуазного общества. М.: Издательство «Весь Мир», 2016.; Хабермас Ю. Между натурализмом и религией. Философские статьи/ пер. с нем. М.Б. Скуратова. М.: Издательство «Весь Мир», 2011

[59] Butler. J. 1997. Excitable Speech: A Politics of the Performative. Routledge: New York and London; Schwartzman, L.H. 2002. Hate Speech, Illocution, and Social Context: A Critique of Judith Butler. Journal of Social Philosophy, 33. pp. 421-441.

[60] Dahlberg L. Visibility and the Public Sphere: A Normative Conceptualisation, Javnost - The Public, 2018, 25:1-2, pp. 35-42. Thompson J. B. Shifting Boundaries of Public and Private Life// Theory, Culture & Society. 2011, V. 28 (4), 49–70; Couldry N. Mediatization or mediation? Alternative understandings of the emergent space of digital storytelling// New media & society, 2008, 10 (3), pp. 373-391.

sphere, but also the emergence of new approaches to understanding disability that has appeared after the arrival of international non-commercial organizations in Russia and the emergence of local public initiatives[61]. These trends have opened the space for public discussion and offered different interpretations of the category.

In addition, in the indicated time period, the UN Convention on the Rights of Persons with Disabilities was ratified and signed (May 2012), which became a critical point in the establishment of social and human rights models of disability in the Russian public sphere, along with the historically entrenched medical interpretations and ideological metaphors of disability[62]. To analyze the modes of agency, the nature of the "mediatized" publicity, the narratives of activists with disabilities, and stories published in Russian media and social networks are studied.

The *subject* of the dissertation research is an integrative analytical concept that explains the key dimensions of the category of disability as a discursive construct and agency mode in the modern public sphere.

Theoretical framework

The dissertation research systematizes and revises theories of the public sphere and discursive theories of disability understanding, the concepts of identity and citizenship. Taking into account the accumulated knowledge and current trends in disability research, the author relies on the classical theory of communicative rationality and the model of the public sphere by J. Habermas[63] and its modern criticism[64] for a comprehensive explanation of the structural changes in the Russian public sphere in recent decades. Summarizing the arguments of criticism, the author considers, first of all: 1) changes in the formats, content, and styles of public discussions about disability in the "mediatized" public sphere, 2) the potential of communicative rationality of the public sphere in overcoming structural inequality, constructing different types of disability agency, 3) conflict dimensions of the public sphere and the effects of public scandals.

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[61] Fröhlich C. Civil society and the state intertwined: the case of disability NGOs in Russia// in: Social Movements in Post-Communist Europe and Russia. L.: Routledge, 2014; Цеханович М. Что мешает развитию социального партнерства в России? Сравнительные общественных организаций инвалидов// Социальная политика в современной России: реформы и повседневность/ Под ред. П. Романова и Е. Ярской-Смирновой. М.: ООО «Вариант», ЦСПГИ, 2008. С.368-389

[62] Ярская-Смирнова Е.Р., Романов П.В. Герои и тунеядцы: иконография инвалидности в советском визуальном дискурсе // Визуальная антропология: режимы видимости при социализме / Под ред. Е.Ярской-Смирновой, П.Романова. М.: Вариант, ЦСПГИ, 2009. С. 289-331

[63] Хабермас Ю. Структурное изменение публичной сферы: Исследования относительно категории буржуазного общества. М.: Издательство «Весь Мир», 2016.; Хабермас Ю. Между натурализмом и религией. Философские статьи/ пер. с нем. М.Б. Скуратова. М.: Издательство «Весь Мир», 2011.

[64] Dahlberg L. The Habermasian public sphere: Taking difference seriously?// Theory and Society, 2005, 34, pp. 111–136.

Finally, the analytical framework of the study is supplemented by the arguments of the agonistic and multiple publicity theories by Ch. Mouffe[65] and N. Fraser[66], the constructionist concept of publicity by A. Young[67], as well as the theories of scandal by J. Thompson[68] and A. Adut[69]. The understanding of agency modes, methods of collective and individual self-presentation of persons with disabilities in the Russian public sphere is based on a revision of the categories "structure" and "agency"[70], modern criticism of classical concepts of identity using the theory of "self as narrative" by A. Giddens[71], the concepts of identity and intimacy in the networked society by M. Castells[72], R. Brubaker and F. Cooper's process approach[73] to the study of identification and categorization, N. Frazer[74] and T. Shakespeare[75] identity models. Stories of intimate citizenship[76] constructed in the hierarchies of discourses of family, gender, body, and sexuality are considered as new foundations for building a project of identity in the mediatized public sphere.

We propose to conceptualize the public sphere, on the one hand, relying on the classical definition of Habermas, as an intersubjective space of action based on the principles of communicative rationality[77]. On the other hand, following the modern criticism of the classical concepts of publicity, as a technology-mediated space of digital publics that also act materially[78].

To reveal the possibilities and limitations of the existing theoretical models of disability, a comparative analysis of the interpretations of the category in the field of disability studies was carried out. Based on the performed analysis, the discursive paradigm[79] of understanding disability was chosen as the most relevant to the integrative concept. Following this approach, disability is

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[65] Муфф Ш. К агонистической модели демократии// Логос, 2004. 2(42).

[66] Fraser N. Rethinking the Public Sphere: A Contribution to the Critique of Actually Existing Democracy// Social Text, 1990. 25/26, pp. 56-80; Fraser N., Nash K. Transnationalizing the Public Sphere. Polity Press, 2014.

[67] Young I. 2000. Inclusion and democracy. Oxford New York: Oxford University Press; Young I. Communication and the Other: Beyond Deliberative Democracy' in Democracy and difference: contesting the boundaries of the political// Democracy and difference: contesting the boundaries of the political/ by S. Benhabib: Princeton Univeristy Press, 1996. pp. 120-35.

[68] Thompson J.B. Political Scandal: Power and Visability in the Media Age. Wiley, 2000; Thompson, J. B. Shifting Boundaries of Public and Private Life// Theory, Culture & Society, 28(4), 2011. pp. 49–70.

[69] Adut A. A Theory of the Public Sphere// Sociological Theory. 2012. V. 30 (4). pp. 238-262; Adut A. On Scandal: Moral Disturbances in Society, Politics, and Art. New York: Cambridge University Press, 2009.

[70] Giddens A. The Constitution of Society, Berkley, CA: University of California Press, 1984; Hays S. Structure and Agency and the Sticky Problem of Culture. Sociological Theory, 12(1), 1994, pp. 57-72; Connor S. Structure and agency: A debate for community development?// Community Development Journal, 2011, 46(S2), pp. 97-110.

[71] Giddens A. Modernity and Self Identity: self and society in the late modern age. Cambridge: Polity Press, 1991

[72] Castells M. The Power of Identity. Malden, MA: Blackwell, 2004.

[73] Brubaker R., Cooper F. Beyond "identity"// Theory and Society 2000, 29, pp. 1–47.

[74] Fraser N. Rethinking Recognition: Overcoming Displacement and Reification in Cultural Politics // Recognition Struggles and Social Movements / ed. by B. Hobson. Cambridge: Cambridge University, 2003.

[75] Shakespeare T. Disability Rights and Wrongs. London, New York: Taylor & Francis Group, 2006.

[76] Plummer K. Intimate citizenship: Private decisions and public dialogues. Seattle: University of Washington Press, 2003.

[77] Хабермас Ю. Между натурализмом и религией. Философские статьи/ пер. с нем. М.Б. Скуратова. М.: Издательство «Весь Мир», 2011.

[78] Varnelis K. Networked publics. Cambridge, MA: MIT Press, 2008; Papacharissi Z. A Networked Self: Identity, Community, and Culture on Social Network Sites (1st ed.). Routledge, 2010.

[79] Corker M., French S. 1999. Disability discourse. Buckingham; Philadelphia, Pa.: Open University Press.; Grue J. 2015. Disability and Discourse Analysis. London: Routledge.

revealed in the dissertation research as a subject of existing social and linguistic conventions. The concept of discourse, in turn, is interpreted as public communication on topics related in one way or another to the phenomenon of disability. Communication is initiated by social agents who are guided by specific interests, values, and beliefs[80]. This approach allows us to identify the role of social and linguistic constructs that determine the interpretation of disability experience. In particular, we are interested in the space of texts, symbols, and signs that represent disability in mediated public interaction.

Methods of data collection and analysis

To develop an integrative concept for the study of the category of disability in the public sphere, based on the accumulated experience of theorizing the issue, we rely on the analytical traditions of the case study[81] combined with expert interviews, analysis of autobiographical projects of persons with disabilities, as well as personal stories published on social media. This combination of methods makes it possible to contextualize the category of disability following the social and technological transformations of the modern Russian public sphere.

The author of the study conducted 15 expert interviews with journalists, activists of public organizations, media experts, curators of museum projects, and representatives of the parent communities. During the interview, the key changes that took place in the institutional field, social perceptions, and media representations of disability were discussed. Specific attention was paid to the particular social and journalistic projects, cases of public scandals. The limitations of the interview results are related to the availability and affiliation of experts. All the experts represented large Moscow organizations and foundations, parental networks, popular media, and leading NGOs.

The analysis of expert interviews was supplemented by an interpretive analysis of stories of persons with disabilities in Russian mass and social media, as well as the study of significant autobiographical projects in recent years (2012 - 2019). Media narratives included personal and co-authored stories of people with disabilities published by popular online media (Wonderzine, Meduza, Takie Dela [Such Matters], Neinvalid.ru, Miloserdie.ru, 2016–2019), narrated in autobiographical projects ("Istoriya Bolezni" [The Disease History] by I. Yasina and "Istoriya

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[80] Ferree, M.M., Gamson, W.A., Gerhards, J. & Rucht, D. (eds) Shaping Abortion Discourse: Democracy and the Public Sphere in Germany and the United States. New York: Cambridge Univer- sity Press. P. 9

[81] Yin R. K. 2014. Case Study Research Design and Methods (5th ed.).Thousand Oaks, CA: Sage Publications; Creswell J. W. 2007 Qualitative Enquiry and Research Design: Choosing Among Five Approaches, Thousand Oaks, CA: Sage Publications.

odnogo pereloma" [The Story of a Break] by E. Voskoboinikova), as well as emerged on social media and online forums (website and forum Neinvalid.ru, posts on Instagram, YouTube vlogs).

Relying on the tradition of the case study, public scandals on disability issues in the Russian public sphere from 2006 to 2017 (6 cases) were analyzed. Cases of scandals are defined in the study as a public space of the collision of multidirectional discourses of disability and the transgression of social norms, a mode of "extreme" publicity of the discussion on disability issues.

The sample of cases was formed according to the logic of the analytical case study[82] (theoretical sample). The selection of cases took into account the above-mentioned significant dimensions of disability discourses and modern publicity, discursive theories of disability, concepts of identity, and theories of scandal. The sample of cases was supplemented as the theoretical framework of the study was revised and the research tasks were clarified.

In this regard, the following characteristics were taken into account when selecting cases:

1) Emergence of different modes of agency of people with disabilities. In all the selected cases, people with disabilities act as key agents of the discussion or their opinion is represented by close social groups, non-profit organizations, informal associations and communities, digital publics.

2) Spatial and structural characteristics of the public sphere, described in the studied theories. Various types of public spaces are presented - TV shows, mainstream media and tabloids, thematic online media, expert platforms, ethical commissions, NGO sites, professional and sports associations, and social media.

3) Temporal measurements of cases to study the transformation of social practices and attitudes before and after the ratification of the UN Convention on the Rights of Persons with Disabilities in Russia in 2012. At the first stage, a step of three years was used in the selection of cases (2006 - the case with the song "Lyudi Invalidy"; 2009/2010 - scandal with the article by A. Nikonov). At the next stages of the study, the intensification of public scandals was observed, thus we narrowed the period of cases selection to one year (2015 - the case with Oksana Vodianova in the Nizhny Novgorod cafe; 2016 - the case with the column by the KP's chief editor about Nick Vujicic and his visit to Moscow; 2017 - the case in the show "Minute of Fame" with the dancer E. Smirnov).

4) Duration of the discussion of the particular case in the media and the successive inclusion of new actors (public figures and opinion leaders, politicians and journalists, activists with disabilities, NGOs, professional and informal communities), as well as the types of public spaces described above.

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[82] Yin R. K. Case Study Research Design and Methods (5th ed.). Thousand Oaks, CA: Sage Publications, 2014.

5) The presence of actions to socially control the situation: the dismissal of the "guilty" actors, a ban on the publication or removal of content, a public apology, etc.

The procedure included the interpretation of the event and its context, timeline and dynamics analysis, the study of key actors and audiences, discourses of disability and types of rhetoric referring to them, as well as the effects of scandal.

The limitations of the case study consist in the selection of the large-scale cases of scandals, which were mentioned in interviews by the experts themselves and, as a rule, concerned the general Russian agenda without taking into account "local" topics.

Sociocultural context and main stages of research

At the first stage of the study, the author's attention was drawn to the cases of public scandals (from 2006 to 2015), which reflect the change in the public rhetoric of the key agents of opinion on the part of the state and social institutions, as well as the ways of mobilization and the processes of constructing the collective identity of persons with disabilities and associated communities in response to stigmatizing media rhetoric and cases of rights violation[83].

The case studies were theorized based on a comparative analysis of the classical theories of the public sphere by J. Habermas and H. Arendt and the concepts of identity by T. Shakespeare ("political" model of identity) and N. Fraser ("status" model of identity) (Article A). The author sought to describe different modes of public participation of people with disabilities in the selected cases of collision of the conflicting discourses of disability.

First, it is the model of overcoming stigmatizing discourses by turning stigma into a tool for building collective identity (according to T. Shakespeare). This model of public participation and collective identity building is illustrated by the analysis of the discussion of the t.A.T.u. song "Lyudi Invalidy" in a talk show on the primary federal channel (2006) and the contradictory rhetoric of the hosts of the "Boliachki" program on Mayak radio (2012) (Article A).

Second, it is the model of struggle to recognize one's position as equal and to oppose systemic inequality within the framework of the "status model" N. Fraser. This model emerged in the case with the article of the journalist A. Nikonov "Finish them off, so they don't suffer!" (2009-2010) and the case with Oksana Vodianova in the Nizhny Novgorod cafe (2015) (Articles A and Г). These cases show how the accumulated social, economic, and the symbolic capital of the scandal actors serve as a resource to resist systemic inequality and stigma (mobilization of the

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[83] Вербилович О. Е. Механизмы формирования идентичности в публичной сфере инвалидности // Журнал исследований социальной политики. 2013. Т. 11. No 2. С. 251-277

professional medical community and NGOs, parental self-help groups, blogger and celebrity activities). The comparative analysis of the rhetorical strategies of the scandal actors (based on the constructionist theory by P. Ibarra and J. Kitsuse[84]), as well as measures for scandal regulation (from 2006 to 2015), reflects the changes in the rhetoric and actions of officials, media figures and journalists following the ratification of the UN Convention on the Rights of Persons with disabilities in Russia.

The diversification of conversation on disability issues in the Russian public sphere in the next 5 years has led to the need to develop a typology of public spaces in which the discussion is being constructed. In particular, the presented articles reveal the analytical potential of Adut's typology of public spaces (Article Б)[85]. It is shown how the complex architecture of "prestigious" and "peripheral" public spaces determines the modes of visibility and set of resources of public participation of different agents of opinion, which produce and reproduce the corresponding discourses of disability. The boundaries between the concepts of "public discourse" and "public sphere" are considered. It is noted that each type of public space determines its own structure of actors, channels, narratives and rhetoric styles, as well as the effects of discussion.

The work done on the previous stage made it possible to form a sample of expert interviews based on the type of public space in which the informant's agency is manifested (NGO activist, journalist, media expert, representative of the parental community, curator of the art platform). Based on the analysis of the interview results, it was possible to present a typology of discourse conventions that shape the discussion about disability in the studied types of public spaces and communities (Fig. 1). In analyzing interviews and personal stories, the author paid particular attention to the ways the disability category was defined by experts, activists, journalists, and personal accounts on social media.

At the same stage of the study, the selection of scandals was supplemented by the column of the chief editor of "KP" E. Arsyukhin about Nick Vujicic and his visit to Moscow (2016) and the scandal in the show "Minute of Fame" with dancer E. Smirnov (2017). The choice of these cases was inspired by the theories of the "mediatized" public sphere (Thompson) and an attempt to comprehend new directions of public discussion on disability issues in Russia. In reflecting the changes, the structural and technological characteristics of the selected scandals (based on an

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[84] Ясавеев И.Г. Конструирование «не-проблем»: стратегии депроблематизации ситуаций // Журнал социологии и социальной антропологии. 2006. Т. 9, №1. С. 91-102.

[85] Вербилович О. Е. Режимы и форматы видимости категории инвалидности в публичной сфере // Вестник Томского государственного университета. Философия. Социология. Политология. 2017. № 37. С. 204-213.

expanded sample) were studied, as well as the repertoire of reactions of various publics (Article Г)[86].

New cases revealed the dramaturgy of the "mediatized" public scandal. In the mediatized public sphere, the discussion is carried out in a complex architecture of social media, which, due to their participatory potential[87], involve a large number of opinion leaders and "ordinary" commentators simultaneously. For example, the case with E. Smirnov in the TV program "Minute of Fame" (2017) was reproduced by a large number of microbloggers and social media users on Facebook and YouTube. The network logic illuminates a situation where an ordinary user or opinion leader presents his interpretation of the case and offers his audience a space for discussion, multiplies the modes of visibility of the topic and event, as well as communicative genres and conversation resources. The described stage of the study explains the structural changes in publicity and discussions on disability issues in the Russian public sphere.

The final stage of the study stepped back to the categories of "agency" and "identity" based on the analysis of personal stories of people with disabilities in social media, autobiographical projects and online media publications[88] (Article B). This line of research continued the reflection outlined by critics of the classical concepts of the public sphere concerning the changing formats, content and styles of public discussions on disability issues in the "mediatized" public sphere. Analysis of narratives about sexuality and acceptance of one's body in social media accounts has supplemented the notions of the peculiarities of the functioning of "digital publics"[89], made it possible to explain the potential of storytelling in overcoming rigidly fixed cultural stereotypes of asexuality (or "abnormal" sexuality).

Contribution to the discussion of the problem in existing literature and statements to be defended:

1. The research presents the author's integrative framework of disability theorization in the context of social and technological transformations of the Russian public sphere in the last two decades. The author's approach is based on the revision of classical and modern theories of the public sphere, discursive theories of disability and social identity concepts. This integrative framework allows us to explain how disability becomes a structure-forming category of the public sphere, taking into account the features of the

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[86] Вербилович О. Е. «Запрещенный прием»: инвалидность и публичный скандал в традиционных и интернет-медиа // Мониторинг общественного мнения: Экономические и социальные перемены. 2018. № 1. С. 253-266

[87] Burgess J., Green J. (2009) YouTube: Online Video and Participatory Culture. Cambridge, UK: Polity Press.

[88] Iarskaia-Smirnova E., Verbilovich V. "It's No Longer Taboo, is It?" Stories of Intimate Citizenship of People with Disabilities in Today's Russian Public Sphere// Sexuality & Culture 24, 2020, pp. 428–446.

[89] Varnelis K. Networked publics. Cambridge, MA: MIT Press, 2008; Papacharissi Z. A Networked Self: Identity, Community, and Culture on Social Network Sites (1st ed.). Routledge, 2010.

mediatization of "public" and "private" dimensions. The research develops a reflection of the modes of agency of persons with disabilities and manifestations of the relevant communities in the "mediatized" public sphere.

2. The created integrative framework explains the types of discursive conventions that determine the fields of meanings attributed to disability by different groups of agents in the Russian public sphere. The author's typology of the conventions for understanding disability is built in the study based on the insights from 15 expert interviews and secondary sources analysis. For the first time, the tendency of abandoning the category of disability as a way of establishing the identity project is revealed. This trend illuminates a new format of politicization of the category by people with disabilities themselves, their communities and informal social networks.

3. The proposed author's theoretical and methodological framework applied to the analysis of the narratives of persons with disabilities on social media interprets the reflexive narratives of intimacy of the disabled body. The analysis shows that the denial of the right to have sexual life persists and is encouraged by the state and family. Nevertheless, the mediatized public sphere offers spaces for constructing personal identity project. Acceptance of the self and body becomes a public and political statement in the stories of people with disabilities on social media.

4. The conflicting dimensions of the public sphere have been explored based on the case study data analysis (6 scandals from 2006 to 2017) supplemented by the interpretative analysis of the media representations and personal narratives on social media. The author's methodological framework to analyze the case of a public scandal has been created. The procedure includes an interpretive analysis of the timeline, context and dynamics of the event, the study of key actors and audiences, discourses of disability and types of rhetoric referring to them, as well as the effects of scandal interpretation. The results of the case study and expert interviews saturate classical and modern theories of the public sphere with an analysis of the disunity of interests of different political and generational activists' cultures in the Russian public sphere. Scandal theories (J. Thompson, A. Adut) are updated by a revision of the types of scandals on disability as a construct of the debate among publics and counterpublics. The role and functions of the scandal as a mode of maximum publicity of the conversation about disability are problematized and interpreted. The tendencies of commodification of public conversation about disability as a resource of the symbolic policy of the state and media attention economy are revealed.

5. The analysis of parental and professional grassroots initiatives as «strong» publics capable of spontaneous and effective mobilization in a situation of public scandal is carried out. The concept of "repertoire of public reactions" in a scandal situation has been developed. The proposed repertoire of public reactions allows us to describe and explain the ways of participating in the discussion according to the degree of reflection and the nature of the reverse action. The repertoire varies from the choice of the position of "tacit" observation to public censure, which can be followed by a significant public action such as an online petition initiation, a collective protest, a dialogue at the level of significant social institutions, legal proceedings, and prohibitive sanctions.

Results

1. Both classical and modern theories rely on the category of "visibility" to describe the normative criteria of publicity. This category is given special attention in modern theories to consider key features of the mediatized publicity. Conceptualization of the category of disability is developed with a revision of the normative criteria of publicity proposed in modern theories of the public sphere ("modes of visibility"[90]) and based on the author's typology of the modes of visibility of the topic, representations of disability, and persons with disabilities' actions in the Russian public sphere. Three key dimensions are considered: space of the discussion, key agents and types of publics, types of discourse conventions. Revision of the existing theoretical models of the public sphere contributes to the integrative approach of the category of disability study with the following normative criteria:

- *recognition of the disagreement* mode as a basis for the publicity theorization (following Mouffe's arguments[91]), as well as the role of "new" media in the authentic representation of the conflict between different publics and counterpublics, in contrast to the stylization of disagreement and commodification of public debates in "old" media (described by P. Bourdieu[92]);

- *recognition of the diversity of agency modes and deliberation styles* (following Young and Dahlberg's arguments): not only rational-critical discussion in terms of Habermasian public sphere, but also storytelling (by Young and Trevisian), aesthetic-affective modes of communication by Dalberg[93] (such as dance, photography experience, theatrical experience,

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[90] Dahlberg L. Visibility and the Public Sphere: A Normative Conceptualisation// Javnost - The Public, 2018, 25:1-2; Adut A. A Theory of the Public Sphere// Sociological Theory. 2012. V. 30 (4). P. 251-252

[91] Mouffe Ch. "Hegemony, Democracy, Agonism and Journalism: An Interview with Chantal Mouffe." Interviewed by Nico Carpentier and Bart Cammaerts// Journalism Studies, 2006, 7(6); pp. 964–975.

[92] Бурдьё П. О телевидении и журналистике / пер. с фр. Т. Анисимовой, Ю. Марковой; отв. ред. предисл. Н. Шматко. М.: Фонд научных исследований "Прагматика культуры", Институт экспериментальной социологии, 2002.

[93] Dahlberg L. The Habermasian Public Sphere: Taking Difference Seriously?// Theory and Society, 34(2), 2005. pp. 111-136.

interaction with the museum space, etc.). These dimensions are especially relevant for the empirical measurement of agency modes in the public sphere, the performative practices of disability representation, and personal stories of disability in the "new" media[94].

- *practices of control and participatory characteristics* of the public interaction: social attitudes and technological conditions to control visibility modes (following Thompson's arguments and the ideas of post-publicity theories[95]). Physical co-presence is no longer the main criteria for participation in the public sphere. However, the practices of controlling private and public, as well as technological barriers to access digital spaces create new grounds for the inclusion or exclusion of opinions and actions, representations of disability.

2. The results of expert interviews with informants representing different spaces of public discussion, styles of deliberation and modes of agency (from the classical "impartial" expertise to the aesthetic styles of art projects) allow us to present a typology of discursive conventions[96] that define the understanding of the category of disability in the public sphere (Figure 1). The studied conventions can both reproduce existing cultural models of disability understanding - cliché definitions, and offer alternative ways to (re)define disability in the spaces of sociocultural and art projects - "flexible" definitions. Moreover, the study exposes the recent movements of rejecting disability as a prior category for identity construction.

Cliché definitions reduce the understanding of disability and shift the emphasis towards a single dimension of the category in terms of medical ("illness", "severe health condition"), social policy and legal ("receiving state assistance", "person in need"), mass media ("hero", "victim") discourses. The *"flexible" definitions* opposed to this type of conventions indicate, first of all, the fluidity of the boundaries of the norm. The multifaceted experience of disability and the successful performance of various social roles - professional, family, civil - are emphasized (for example, in the autobiographical projects by I. Yasina and E. Voskoboinikova). Moreover, in these flexible patterns the experience of disability is aestheticized, becoming the subject of reflection in creative projects of theater, cinema, photography (the festival "Cinema without barriers", the project "Protheatr", the project of contemporary art "The Common Whole"). At the same time, a relatively new trend noted in the course of expert interviews is *the rejection of the category* of disability in public discussions and the narrated project of identity. Disability in this movement doesn't

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[94] Iarskaia-Smirnova E., Verbilovich V. "It's No Longer Taboo, is It?" Stories of Intimate Citizenship of People with Disabilities in Today's Russian Public Sphere// Sexuality & Culture 24, 2020, pp. 428–446.

[95] Hogan B. The Presentation of Self in the Age of Social Media: Distinguishing Performances and Exhibitions Online// Bulletin of Science, Technology & Society, 2010, 30(6), pp. 377–386; Bohman J. Beyond Distributive Justice and Struggles for Recognition: Freedom, Democracy, and Critical Theory// European Journal of Political Theory, 2007, 6(3), pp. 267–276.

[96] The concept is conceptualized using the resources of modern discursive theories of disability (Grue, 2015; Corker & French, 1999), which largely rely on the traditions of critical discourse analysis and borrow the term "topoi" from the paradigm of the historical CDA - prescriptions regarding the content of the statement and the connection of its arguments with the conclusion (Wodak, 2006: 74)

determine the agency. The structure of collective action takes into account the multiplicity of individual experiences as the starting point for a conversation about the universal design of education, city infrastructure, and museum spaces, etc.

"flexible" definitions

cliché definitions

rejection of the category

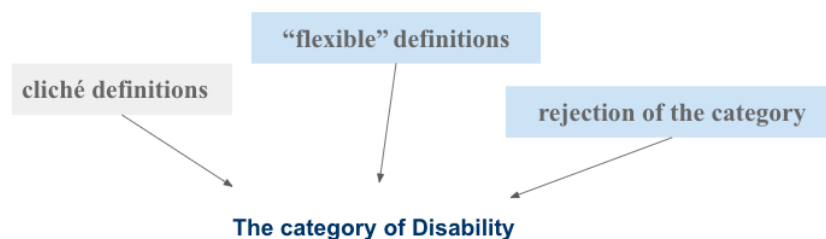**The category of Disability**

Figure 1. Types of the discursive conventions

3. The traditions of identifying society with the state in the Soviet culture predetermined the tendency to politicize not only public representations of disability, but also the dimensions of the private and intimate. In particular, sexual life in the Soviet project of society wasn't considered as personal domain but was treated as a sphere of state interest[97]. The analysis of interviews, representations of sexuality and disability in the mass media, as well as the intimate narratives of persons with disabilities in social media shows that the denial of the right to have sexual life persists and is encouraged by the state and family. Intimacy issues are either not voiced under the pressure of cultural stigma or labeled as unworthy of public discussion.

Another important issue that reflects the agency's structural constraints is the discussion of moral and spiritual values that govern beliefs about sex and socially acceptable sexual behavior. Stable stereotypes of "asexuality" of persons with disabilities, combined with the religious values prescribing the disabled body the meanings of spiritual and "moral purity of the suffering" become regulators of everyday judgment and behavior. These attitudes are demonstrated by persons with disabilities themselves, and also by the professionals, parents, volunteers, and activists who form their social environment. Fragments of personal stories of disability in mass media and social networks show that the ideas of "spiritual sacrifice" and the "abandonment of the body" become the most 'legitimate' motifs to deny the demand to seek safe space and resources to build sexual identity of a disabled person.

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[97] Кон И. С. О социологической интерпретации сексуального поведения // Социологические исследования. 1982. № 2. С. 113-122.

Although, the very appearance of such personal stories in public spaces opens up opportunities for a reflexive revision of one's own sexuality[98] and participation in a collective project of social change, directed by grassroots initiatives of intimate citizenship[99]. Persons with disabilities, as passive or active agents of narration, try to go beyond the narrow boundaries of the category of disability and resist the images that stigmatize them.

To a greater extent, this reflexive process is facilitated by the "flexible" performative spaces of the mediatized public sphere, i.e., personal accounts on social networks, popular online media projects (personal stories in Wonderzine, Takie Dela, Meduza), autobiographical stories, communities on social networks, and forums. The visibility of personal stories in the public sphere reveals spaces of collective identity building to change perceptions of sexuality at a structural level, touching upon the "millennial historical and cultural foundations of sexual prohibitions and forced heterosexuality" [100].

The coexistence of cultural taboos, methods of social control of corporeality and personal narratives in the space of the Russian public sphere sets the conditions for the structural transformation of publicity. The narrative becomes a resource for the politicization of sexuality not only on behalf of the institutional practices of the state and medicine as it was in the soviet past, but on the part of other significant agents of public discussion, among which, first of all, people with disabilities make themselves visible. They propose the conventions for understanding one's body and sexuality that are becoming a new symbolic and ideological form of communication, and a cultural pattern that structures public interactions.

4. Recognition of the theoretical and empirical significance of the conflicting dimensions of publicity allows us to rely on the results of the study of a public scandal as a discursive event in which different types of publics and counterpublics participate at the same time, asserting or challenging the prevailing understanding of disability. The analysis of six cases of scandals in the Russian public sphere from 2006 to 2017[101] reveals the contexts of blurring boundaries of the public, private and intimate, in the "mediatized" public sphere.

First, such cases combine diverse and often not encountered with each other public spaces, from a staged discussion in a TV show, a resonant newspaper article with an audience of thousands to individual or collective Internet petitions, discussions on social networks and personal "vlogs". Secondly, the moral and emotional load of statements, as well as the spontaneous nature of the transgression, simultaneously involve a large number of participants, who are forced

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[98] Giddens A. 1991. Modernity and Self Identity: self and society in the late modern age. Cambridge: Polity Press.
[99] Plummer K. 2003. Intimate citizenship: Private decisions and public dialogues. Seattle: University of Washington Press.
[100] Castells M. 2009. Communication Power. New York: Oxford University Press. P. 279.
[101] Вербилович О. Е. 2018. «Запрещенный прием»: инвалидность и публичный скандал в традиционных и интернет-медиа // Мониторинг общественного мнения: Экономические и социальные перемены. № 1. С. 253-266.

(for example, high-profile public figures) or have received a special opportunity, to speak and join the public discussion. The topic itself, as a result of such a transgression, acquires maximum publicity. A space for discussion, rethinking or strengthening of cultural norms, opens up. Both grassroots actors and informal networks as far as influential speakers and prestigious public spaces with an accumulated resource for mobilizing attention are simultaneously involved in the discussion.

The research analyzes "accidental" scandals[102], which, however, have long-term effects. In particular, some scandals considered became an example of an institutionalized public debate about the norms and rules of public discussion on disability. The key actors of the conflict, the journalistic and civil communities equally participated in this debate. Such cases can continue for several years, involving new platforms and topics to discuss and performing public self-regulation functions in the discussions of moral, ethical and professional issues.

Dividing lines of counterpublics, the growing importance of symbolic politics, and image-management of the opinion leaders[103], manifestations of "manipulative" publicity[104], which is set by the latent interests of the state and market structures, shape the environment of scandal as the conflict mode of communication. Scandal regulation strategies and public reactions can be distinguished by the nature of the reverse action and the degree of reflection (Figure 2). At the level of private everyday practices, one can make the choice of both the position of the "silent" observer, or practice verbal condemnation, which can be followed by a significant public action, such as the initiation of an Internet petition, a collective protest, institutional dialogue, court proceedings, or prohibitive sanctions.

Scandal regulation strategies and public reactions	
By the nature of the reverse action	• From third-party surveillance to strategies for removing any content • From verbal condemnation to collective protest • Repressive sanctions, scapegoating, dismissal of journalists, editors, etc.
By the degree of reflection	• Affective participation: from emotional judgment to reproduction of stereotypes; transformation and transfer of rhetoric to other contexts (or other actors) • Reflexive participation: striving to understand the foundations of ethical paradox and find ways to resolve it, search for conventions and rules of speaking and interaction (examples of publications on ethical norms and rules of communication with different social groups in Meduza, Wonderzine, Takie dela, etc.)

Figure 2.
The repertoire of public reactions

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[102] Adut A. A Theory of Scandal: Victorians, Homosexuality, and the Fall of Oscar Wilde// American Journal of Sociology, 2005, 111 (1). pp.213-248.

[103] Adut A. A Theory of the Public Sphere// Sociological Theory. 2012. V. 30 (4); Малинова О. Ю. Конструирование смыслов: Исследование символической политики в современной России. М.: ИНИОН РАН, 2013.

[104] Habermas. 1991. The Structural Transformation of the Public Sphere/ T. Burger and F. Lawrence (trans). Cambridge, MA: MIT Press. P. 211–222

5. Habermas's definition of the public sphere as "a field of tensions between the state and society"[105], problematizes another vector of conceptualizing the category of disability such as collaboration or contradictions between the institutions of power (the "official" public sphere), and institutions of civil society (the "grassroots" public sphere). The key agents of the "official" public sphere in Russia are the Presidential Administration, the Presidential Council for Disabled Persons (which operated in 1996-2001), the State Duma, the Ministry of Health and the Ministry of Labor and Social Protection of the Population, the All-Russia People's Front (ONF) and the Public Chamber, political parties, institutes of social and medical rehabilitation. As studies of the category of disability in the post-Soviet public sphere show[106], the nature of interactions between the "official" public sphere and non-governmental advocacy organizations, communities of people with disabilities, and parental self-help groups in post-Soviet countries, can be described both in terms of social partnership and political conflict. The case-study of public scandals suggests that the most mobile and cohesive agents of the grassroots Russian public sphere are parental communities, both self-organizing and NGO based. Parental initiatives, from time to time, manage to build successful collective action and online campaigns in defense of the rights of children with disabilities, representing the interests of the community in dialogue with the media and the state[107].

The study emphasizes several key strategies for mobilizing the parental community in the Russian public sphere, reflecting different agency modes of the parental networks:

- grassroots self-organization, which grows into a constantly functioning public organization actively lobbying for disability topics in the public sphere;

- NGO based: self-organization around the projects of an existing non-governmental organizations and funds;

- online activities of parents in social media, which can complement the above-mentioned practices, take forms of digital activism or perform self-help groups' functions

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[105] Хабермас Ю. 2016. Структурное изменение публичной сферы: Исследования относительно категории бур-жуазного общества. М.: Издательство «Весь Мир». С. 80

[106] Fröhlich C. 2014. Civil society and the state intertwined: the case of disability NGOs in Russia// in: Social Movements in Post-Communist Europe and Russia. L.: Routledge; Rasell M., Iarskaia-Smirnova E. R. 2014. Conceptualising Disability in Eastern Europe and the Former Soviet Union, in: Disability in Eastern Europe and the Former Soviet Union. History, policy and everyday life / Ed. by E. R. Iarskaia-Smirnova, M. Rasell. NY, Abingdon: Routledge; Oates S. 2013. Parents and Patients. Online Health and Fairness Campaigns in Russia// in Revolution Stalled: The Political Limits of the Internet in the Post-Soviet Sphere by S. Oates. Oxford University Press; Цеханович М. Что мешает развитию социального партнерства в России? Сравнительные общественных организаций инвалидов// Социальная политика в современной России: реформы и повседневность/ под ред. П. Романова и Е. Ярской-Смирновой. М.: ООО «Вариант», ЦСПГИ, 2008. С.368-389

[107] Iarskaia-Smirnova E. R., Romanov P. V., Iarskaia V. N. Parenting children with disabilities in Russia: institutions, discourses and identities // Europe-Asia Studies. 2015. Vol. 67. No. 10. P. 1606-1634; Oates S. 2013. Parents and Patients. Online Health and Fairness Campaigns in Russia// in Revolution Stalled: The Political Limits of the Internet in the Post-Soviet Sphere by S. Oates. Oxford University Press; Вербилович О. Е. (2013). Механизмы формирования идентичности в публичной сфере инвалидности// The Journal of Social Policy Studies, 11(2), pp. 257-272;

- individual and collective online campaigns[108] that have received a wide response in the public sphere

The results of expert interviews and the analysis of the dynamics and contexts of public scandals reveal the most conflicting modes of co-presence and symbolic interaction of the described types of the "official" and "grassroots" publics in the process of constructing the meanings of the category of disability. The historically conflicting nature of relations between the two cultures of social activists and the state in Russia[109] was justified by the activists' assessments in the field work interviews. In addition, the formal differentiation of disability types and advocacy organizations which is rooted in the social policy of the Soviet past still largely determines the conflict dimensions between different generations, communities and disability subcultures.

The ambivalent nature of such gaps is explained by the concept of "hybrid citizenship" [110]. On the one hand, the post-Soviet activists with disabilities tend to articulate demands for social support in the traditions of Soviet social policy, on the other hand, to declare their political rights and demand social partnership in the spirit of neoliberalism. In the phenomenon of "hybrid citizenship" the dichotomy of "structure" and "agency" is most clearly manifested. We observe two oppositely directed tendencies: the desire to "utilize" the category to fit into the structure of historically established political relations between different types of publics, at one end, and the emergence of new constructs of disability to resist the prescribed social norms, an attempt to construct personal identity project, with another end.

Overall, it cannot be said that a consolidated social movement or a community of persons with disabilities, which performs the role of the key agent of public discussions, has developed in contemporary Russia. However, the described actors and spaces of the "grassroots" public sphere actively initiate a discussion in the "official" public spaces such as state institutions and social policy debates, as far as in the "prestigious" media environments. This allows us to speak about the structure-forming role[111] of the category of disability in the process of public communication between the state, civil society, persons with disabilities, and professional and parental communities in modern Russia.

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[108] Школы для инвалидов на грани выживания: что такое «затратные дети»?/ 18.09.2014 М. Лепина Милосердие.ру// https://www.miloserdie.ru/article/roditelskoe-sobranie-chto-takoe-zatratnye-deti/ Дата доступа: 7.03.2020

[109] Fröhlich C. 2014. Civil society and the state intertwined: the case of disability NGOs in Russia// in: Social Movements in Post-Communist Europe and Russia. L.: Routledge; Цеханович М. Что мешает развитию социального партнерства в России? Сравнительные общественных организаций инвалидов// Социальная политика в современной России: реформы и повседневность/ под ред. П. Романова и Е. Ярской-Смирновой. М.: ООО «Вариант», ЦСПГИ, 2008. С.368-389

[110] Phillips S. Representations of disability in print news media in post-socialist Ukraine// Disability & Society, 2012, 27:4, pp. 487–502

[111] Хабермас Ю. Между натурализмом и религией. Философские статьи/ пер. пер. с нем. М.Б. Скуратова. М.: Издательство «Весь Мир», 2011.

Conclusion

The research results reveal how, in the context of recent social, cultural, and technological transformations of the Russian public sphere, the constitutive role of the category of disability as a discursive construct of public conversation among multiple publics has become more robust. The conceptualization of the category in the frames of Russian socio-cultural context of the last two decades contributes to the reflection on the changing boundaries of disability discourses, as well as structural changes in the public sphere itself.

First, the mediatization processes transform one of the key structural characteristics of the public sphere - the modes of "visibility" of the topic, representation of disability, personal or collective action. The personalization features and participatory nature of the new media reveal new modes of agency and visibility of the disability issues. Primarily, digital storytelling is becoming an alternative communication format that allows one to change the framework of "impartiality" or "expertise" and develop the performative style of communication.

Second, the discursive conventions of disability are changing. In the rhetoric of state institutions, disability is discussed in terms of fragmented, rigidly defined concepts, i.e., "diagnosis", "invalid", "beneficiaries of social services", and "vulnerable groups". However, in recent decades, the exclusion and reduction of the category in the contexts of the dominant institutional discourses of the state and the mass media gives way to flexible and variable concepts of understanding the experience of disability in the mediatized public sphere.

Such kinds of alternative spaces produce and make visible personal stories of disability and sexuality, which approve a new stage in the cultural transformation of the public sphere, i.e., the construction of the projects of intimate citizenship and refusal of the category of disability as dominant in self-identification. Intimate stories of disability, both personal and co-authored with journalists, become a political statement, an engine of social change not only in social policy and cultural perception of disability, but also in the culture of public discussions on the taboo topics.

The importance of conflict modes of communication as a normative criterion of the public sphere is recognized. The results of the case study of the discursive spaces of public scandals between multiple conflicting audiences explain the grounds and contexts of subversion of social norms and disability interpretations. Based on the analysis of the empirical contexts of scandals, the concepts of "repertoire of public reactions" and "strategies for mobilizing the parental community" have been developed and theorized. The scandal mode expands the space of discussion on disability, introduces new agents of public speech, makes different publics take a certain transparent position, and invents measures to resolve the situation. However, following the

theoretical tradition of critical theory, this study reveals the foundations of the commodification of the category of disability in the context of public scandal – the process of converting topics and platforms of public conversation about disability into a construct of political technologies and a resource for the media's attention economy.

The next promising research step in line with the proposed integrative concept can be a dense discourse analysis of the content and contexts of communication within the public discussions' types on disability presented in the study. A combined "birds-eye-view", i.e., the mapping of meanings, rhetoric, and confrontational relations, and "from the inside" based on the content of claims could explain the complex interweaving of public spaces and discourses that shape disability. In the broader context, it could also explain the nature of transgression of social norms, symbolic politics, ethical issues of professional communities, and the specifics of public language norms related to the sensitive topics discussion.

Publications

List of author's publications, which reflect the main scientific results of the thesis:

1. Verbilovich O. Mehanizmy formirovanija identichnosti v publichnoj sfere invalidnosti (Identity Forming Mechanisms in Public Sphere of Disability), in: The Journal of Social Policy Studies. 2013, 11 (2): 251-277.

2. Verbilovich O. Modes and formats of visibility of the category of disability in public sphere (Rezhimy i format vidimosti kategorii invalidnosti v publichnoj sfere) // Vestnik Tomskogo gosudarstvennogo universiteta. Filosofiya, sotsiologiya, politologiya – Tomsk State University Journal of Philosophy, Sociology and Political Science. 2017 (37): 204-213

3. Iarskaia-Smirnova E. R., Verbilovich V. "It's No Longer Taboo, is It?" Stories of Intimate Citizenship of People with Disabilities in Today's Russian Public Sphere // Sexuality and Culture. 2020. Vol. 24. No. 2: 428-446.

4. Verbilovich O. "Forbidden trick": disability and public scandal in traditional and online media// The Monitoring of Public Opinion: Economic and Social changes. 2018 (1): 253-266

Other publications on the topic of dissertation:

5. Verbilovich O. Teorija kommunikativnogo dejstvija: kljuchevye kategorii I poznavatel'nyj potencial (The Theory of communicative action: key categories and cognitive potential), in: Public sphere: theory, methodology, case study. Ed. by Elena R. Iarskaia-Smirnova, Pavel V. Romanov. Moscow: Variant, Center for Social Policy and Gender Studies, 2013: 35-52

6. Iarskaia-Smirnova E. R., Prisyazhniuk D., Verbilovich O. Priemnaja semja v Rossii: publichnyj diskurs i mnenija kljuchevyh aktorov (Foster family in Rusiia: public discourse and key actors opinions)/ The Journal of Sociology and Social Anthropology (JSSA). 2015, 4 (81) Ch. VIII: 157-173

7. Verbilovich O. Social'nye osnovanija dlja razvitija diskriminacii v obshhestve (Social grounds for discrimination issues), in: Actual problems in the implementation of the principle of equality of law. European experience: from theory to practice: International conference materials (Minsk, April, 2013) / Office for the Rights of People with Disabilities in Minsk. Ed. By S. Drozdovsky [et al.]. Minsk: 9-14

8. Verbilovich O. Roditel'-grazhdanin: pereopredelenie granic lichnogo I politicheskogo (Parent and citizen: redefinition of the boundaries of political and private issues), in: Sociology and society: globalization and region development. The 4th Regular All-Russian Sociological Congress. Moscow: ROS [Digital resource], 2012

The results of the thesis research were assessed at the 14th International conference of the European Sociological Association "Europe and Beyond: Boundaries, Barriers and Belonging" (Manchester, UK, August 20-23, 2019), at the International conference "Without Barriers 2.0: New approaches to Disability research" (Moscow, NRU HSE, November 16-17, 2018), at methodological seminars during a postgraduate internship at Lincoln University, Lincoln, UK (from January 20 to February 22, 2018), at the International conference "Global mental health and therapeutic assemblages: concepts, controversy and necessary tensions", February 12-13, 2018 at the University of Sheffield, Sheffield, UK. As part of the advanced training program "Teach for HSE", NRU HSE together with the Maastricht University (September 27- December 20, 2017, Moscow). At the conference "Vectors of Modern Russia Development", Moscow Higher School of Social and Economic Sciences, April 20-22, 2017; at the XI All-Russian Scientific Conference in memory of Yuri Levada, April 25, 2017 NRU HSE, Moscow.

The research results were integrated in the author's elective course "Media Scandals Research" for the Bachelor students of the "Media Communications" and "Journalism" academic programmes and for the Master students of the «Critical Media Studies» programme at the Higher School of Economics in 2019 - 2021. The course received high evaluations by students, entering the category of the best elective courses. Thesis results were published in eight articles for Russian and foreign scientific journals, of which one is in Q1 in Scopus, one is in Q3 in Scopus, three is in the list of recommended journals of the HSE, one is in a collective monograph, and two more are in the international conferences proceedings.