

Original research

SOCIAL CONSTRUCTION OF MENTAL DISABILITIES IN RUSSIAN RESIDENTIAL CARE INSTITUTIONS

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ABSTRACT

Introduction: The paper examines the situation of people with mental disabilities currently living in long-term residential institutions in the Russian Federation, with a primary focus on congenital intellectual and developmental disabilities. The goal was to reveal the ways in which contemporary Russian society conceptualizes disabilities by describing the attitudes towards disability of different groups of care-workers in an institutional setting.

Methods: The research is based on qualitative methodology, and the data was collected

mainly by participant observation and analysed using grounded theory methodology.

Results: Two contradictory attitudes to mental disabilities were revealed through lay and professional discourses and social policy-making: the first was a paternalistic medical approach characteristic of representatives of the state residential institutions; and the other was the ideology of normalization and the social model approach, as advocated by nongovernmental organizations and disability rights activists.

Conclusion: Implementation of the normalization principle by grass-root organizations is now partly supported by an official social policy that is slowly turning towards deinstitutionalization, following the western European and North American model of inclusion. The boundaries of the cultural notions of norm and normality have now changed to include a wide variety of individuals who were previously isolated in specialized institutions, labelled as mentally disabled and considered barely human.

Keywords: DEVELOPMENTAL DISABILITIES, ETHNOGRAPHIC RESEARCH, MENTAL RETARDATION, NGO, RESIDENTIAL CARE INSTITUTIONS

INTRODUCTION

This paper touches upon a specific segment of the mental health field and presents a brief overview of the author's socio-anthropological study of residential institutions for people with mental disabilities in the Russian Federation conducted between 2009 and 2011, with a particular focus on congenital intellectual disabilities, referred to in Russian as *mental retardation*.

The goal of the present study was to reveal the ways in which contemporary Russian society conceptualizes disabilities, primarily intellectual and developmental disabilities. This was done by describing the attitudes towards disability and the so-called anomaly of

different groups of care-workers in the setting of Russian long-term care institutions for children and adults with mental and physical disabilities. The article will first describe the context of the research to provide the reader with information about the scope of institutionalization of people with mental disabilities and the institutional settings in the Russian Federation. After a short discussion of the research methods, the results of the study will be presented. In the Russian Federation, a large proportion of people with mental disabilities live permanently in large, state-run residential care psychoneurological institutions. According to data from the Ministry of Labor and Social Security, there are currently 514 residential care institutions for adults with mental disabilities in the Russian Federation, housing 152 000

people, and 131 residential institutions for children with mental retardation (i.e. specialized children's homes), housing 19 600 children (1). For example, St Petersburg, the second largest city in the Russian Federation with a population of about 5 million, has eight residential institutions for adults with mental health problems, each housing 250–1050 people (6000 people in total). There are five residential care homes for children with intellectual disabilities, each currently housing 50–350 children (800 children in total). Study data was partly provided by one of the nongovernmental organizations (NGOs) working with people with disabilities and partly gathered by the author through personal visits to the institutions, studying their websites and analysing official documents available at the St Petersburg Social Policy Committee webpage (2). Based on these figures, around 0.12% of the population of the Russian Federation permanently live in long-term care institutions for people with mental health problems.

According to their official profile, these specialized children's institutions accommodate children with confirmed intellectual disabilities that might be accompanied by disorders including cerebral palsy, epilepsy, visual and hearing impairment, autism and other developmental disabilities. Most children in these institutions show some degree of intellectual disability (from mild to profound), while some have been incorrectly diagnosed as having mental retardation based on physical and speech impairments that are in fact due to cerebral palsy, which does not affect intellectual ability.

In some cases, the Psychological Medical Educational Commission (the state committee authorized for evaluating a child's abilities in the Russian Federation) can revise and overturn a diagnosis of mental retardation when a child leaves the institution at the age of 18 years or is adopted. After children reach legal adulthood, few return to their families or live independently. Most move to a psychoneurological residential institution for adults, where they spend the rest of their lives.

Psychoneurological residential institutions for adults house a more diverse population. According to the only available statistics (which are quite outdated), the largest group of residents (69%) comprises people with two forms of mental disability: different types

of dementia and congenital intellectual disability. In all, 43% of residents with congenital intellectual disabilities are transferred to psychoneurological institutions from children's homes, 25% come from being cared for within the family and 21% are transferred from psychiatric hospitals (3). Other residents of these institutions have either a psychiatric disorder (such as schizophrenia) or a neurological disorder (such as cerebral palsy or epilepsy). Therefore, psychoneurological residential institutions accommodate both psychiatric and neurological patients; this approach was inherited from the Soviet medical and welfare system. This means that people with quite different intellectual abilities and mental health status live together behind the walls of the same building. That is, they are placed together in these institutions based not on their mental health status but rather on their inability to take care of themselves and live independently. All of the residents are labelled as *disabled* or *invalids* (in Russian), meaning they are not fit for a so-called normal life.

Large residential institutions that are the legacy of Soviet social policy remain the only form of residential facility provided by the state for people with moderate or profound mental retardation, some intellectual disability, severe physical disability or multiple disabilities. That is not to say that isolating people with mental disabilities in large residential institutions was unique to the Soviet and post-Soviet eras. In western Europe and North America, such institutions were in existence for more than a century until the 1960s to 1970s, when isolating people with disabilities was deemed a violation of their human rights (see, for instance, Foucault's classic study on the history of conceptualization of mental disability and the institutionalization of mentally disabled people in Europe (4), or Trent's study of the history of institutions for people with mental retardation in the USA (5)). People with disabilities, including mental disabilities, were then gradually deinstitutionalized and the huge institutions were closed. In the Russian Federation, new attitudes towards people with disabilities have begun to take root, and the processes of deinstitutionalization and inclusion have only just started. The current trends resemble the situation in western Europe and North America about half a century ago, although within a different cultural and historical context.

METHODS

The study was mostly based on data from two residential institutions for people with mental disabilities located in the outskirts of St Petersburg: a home for children with intellectual disabilities aged 4–18 years, and a psychoneurological facility for adults.

The residential home for children opened in 1961 and housed about 500 children at the time of the study. The institution for adults opened in 1969 and housed about 1000 people at the time of the study. Thus, the huge institutions for disabled people started to emerge in the Soviet Union just when the deinstitutionalization processes were about to begin in Europe and the USA. People with various disorders and quite different abilities (for example, a physically able person with moderate intellectual disability, a paralysed person with normal intellectual ability and a person with multiple severe disabilities) may live together, under quite crowded conditions, sometimes in a ward housing up to 15 residents. Staff of the institutions who attend the residents daily include attendant nurses, medical staff and instructors. During the day, a group of 12–14 children is usually cared for by a single attendant nurse, often along with an instructor for groups of more active children. Each department of the adult institution houses about 80 people, who are cared for by one or two attendant nurses. The rehabilitation department for the most physically and intellectually able residents is also staffed with a sports instructor and a social worker in charge of cultural activities.

Apart from staff, another group of care-workers who attend the residents daily comprise volunteers and specialist teachers from a charitable NGO that has worked within the institutions since 1996. This is one of few NGOs within the Russian Federation currently allowed to take part in everyday care routines for people with mental disabilities inside the institutions, although a growing number of institutions are gradually opening their doors to volunteer initiatives such as providing classes for residents on weekends or taking them out to the cinema or church. It should be noted that this organization works only with people with congenital developmental disabilities, and not with people diagnosed with senile dementia or schizophrenia, for example.

The major part of ethnographic fieldwork was conducted in the form of participant observation. To

gain access to the field, I joined the community of the NGO volunteers, comprising young people aged 18–30 years from Germany, Poland, the Russian Federation, Switzerland and other countries. This role allowed me to participate in the everyday life of the institutions, which meant that I could observe and analyse not only the official discourses on disability (performed by staff of the institution or members of the NGO) but also the practices and routines of different groups of people interacting with the residents, including their spontaneous actions and utterances. The NGO profile meant that I had to concentrate mostly on people with congenital developmental and intellectual disabilities, which determined the focus of my research. The methodology of the field research, including prolonged participant observation and close work with people in the wards of specialized institutions, was based on the method used by Goffman in a classic qualitative sociological study of a mental hospital (6), one of the first ethnographic works on intellectual disability by Edgerton (7) and Goode's ethnomethodological study of communication with deaf-and-blind children with mental disabilities (8).

Other methods involved prolonged in-depth interviews with representatives of the volunteer community ($n = 17$), NGO administrators ($n = 2$), disability activists and lawyers ($n = 3$), and staff of the institutions ($n = 3$), along with visits to other psychoneurological institutions in St Petersburg (9). The self-observation method was crucial for data collection and analytical procedures, although the volunteer position had some limitations for conducting field research because some respondents viewed the researcher as an adversary. I therefore made special efforts to distance myself from the volunteer community under study (for a full description of systematic self-observation methodology in field research, see Rodriguez and Ryave (10)).

The analytical framework of the research lies within the constructionist perspective and drew upon classic studies into the social construction of mental disability by Goffman (6, 10), Sheff (11), Rosenhan (12) and others. It also took into account critiques of the radical social constructionist approach towards mental illness (see, for example, (13, 14)). In this approach, the social researcher recognizes the physiological nature of disability and disease but their analysis focuses on social conceptualization and professional and lay

stereotypes of disability, and the way in which societal reactions to mental disability form and determine the perspectives and living standards of a person labelled as mentally ill or disabled and thus deviating from the norm.

Each society develops its own institutions to frame abnormalities and incorporate them into the social order. As cross-cultural analysis shows, different cultures can treat anomalies by ignoring or rejecting them or by creating a model of reality in which a place is reserved for so-called deviating individuals (15, 16). Providing a place for deviation forms part of the social construction of the norm. The socio-anthropological interpretation of normality and abnormality differs both from the medical approach to the norm and anomaly and from its lay perception. It allows both norm and anomaly to be viewed as social and cultural constructs; therefore, disability and mental illness can be interpreted not in terms of pathologies and defects but instead as socially constructed categories and notions. This approach implies that the limitations imposed on people with disabilities spring largely from the social environment and not so much from their physical or mental condition. This approach is rooted in the principles of cultural–historical psychology and so-called defectology, as formulated by Vygotsky (17). He showed that mental or physical defects in themselves do not determine the route of a child’s psychological development; rather, it is the interaction of the child with the social environment that determines the consequences of the organic defects. By taking this stance, the article will demonstrate the two types of social construction of disabilities that exist in specialized long-term care institutions in the Russian Federation, and thus the two lenses through which patients in these institutions see themselves and frame their own experiences.

Owing to space restrictions, this article does not aim to review all previous literature on the anthropology of mental disabilities and disability studies in the Russian Federation and post-Soviet space (for examples of socio-historical and ethnographic papers in this field, see (18–21); see also a review of social studies into mental health in the post-socialist space (22)), or the history of institutions for people with disabilities and deinstitutionalization processes in western Europe and North America (for additional information, see (23, 24)): it will only briefly mention

the core papers relevant to the theoretical framework of the study. It is worth mentioning that only a few papers have focused on analysing the social conditions of mental health patients inside long-term care institutions in the Russian Federation (for some examples in Russian, see (25, 26)), and none have employed participant observation methodology, perhaps partly due to difficulties in gaining access to these institutional settings.

Data analysis involved the methods of grounded theory, thick description and discourse analysis (27–29). However, the aim was not to provide a detailed analysis of discourses on intellectual disability in the Russian Federation, but rather to briefly outline the attitudes and practices of social workers within the specialized institutions towards patients with disabilities. A more extended analysis is available in Russian (30, 31).

RESULTS AND ANALYSIS

People working with the residents of the institutions were found to belong to two communities distinguished by their different discourses on disability and mental illness, and having two different sets of practices in their everyday routines. The staff of the institutions (doctors, medical nurses, attendant nurses, instructors) and members of the NGO (volunteers, specialist teachers) have different understandings of the physical and social needs of their patients and their abilities and life perspectives. This has led to two contradictory constructs of disability through which residents of the institutions perceive themselves and frame their own experiences.

Anthropologists who conduct field research into a specific culture or social group usually study emic categories and classifications (i.e. those used by the community under study and reflecting the native point of view). Thus, staff of the institutions classified the residents as walkers, wheelchair users and bedridden patients according to the extent of their physical abilities; in contrast, volunteers prefer to use the terms weak and active. However, it is not only the names that differ – volunteers first consider a resident’s mental ability, rather than their physical characteristics. In addition, adult residents are classified as legally capable or legally incapable, which largely determines

TABLE 1. ATTITUDES TOWARDS RESIDENTS OF MENTAL INSTITUTIONS: STAFF VS VOLUNTEERS

Aspect of construction	Staff views and institutional settings	Volunteers' ideology and practice
Physical treatment	<ul style="list-style-type: none"> · Bedridden children are fed hurriedly in their beds; walkers with "working hands" eat by themselves; adults who cannot eat by themselves are fed by other residents; bedridden residents often do not get enough food and drink, and have no free access to drinking-water · Thorough hygiene is deemed unnecessary; sometimes, diapers are changed only once a day; according to the schedule of the institution, patients are bathed only once a week · Staff are negligent and rude when moving wheelchair users or bedridden patients; rarely, residents are hit 	<ul style="list-style-type: none"> · Volunteers teach even the weakest residents to chew and eat by themselves, when deemed possible by specialist teachers; they feed residents carefully and slowly · Volunteers provide thorough personal hygiene care, using skin-care products and are careful when moving residents
Age	<ul style="list-style-type: none"> · Bedridden children and teenagers are often treated as infants in need of total protection · Adult people with congenital intellectual disabilities are viewed as children in grown-up bodies, according to a popular cultural stereotype 	<ul style="list-style-type: none"> · In adult residential institutions, the volunteer community is actively pushing forward the notion of adulthood to help the residents believe they are grown-up people with adult needs and responsibilities
Gender and sexuality	<ul style="list-style-type: none"> · Gender differences and gender display seem unimportant to staff for bedridden patients · Sexual behaviour in the form of masturbation is tolerated for men/boys, but not for women/girls · Sexual contact is allowed for some legally capable, active adults, but childbirth is prevented 	<ul style="list-style-type: none"> · Volunteers try to dress even those children considered the weakest according to cultural gender stereotypes; they teach active children gender-specific practices and help teenagers and adults in gender display · Volunteers differ in their approaches towards the sexuality of people with mental disabilities, but some acknowledge their right to sex and reproduction
Privacy, private space, personal belongings	<ul style="list-style-type: none"> · Children's personal space is usually limited to their bed; they have no private space to keep their personal belongings; most active children hide their personal belongings in a bag and carry it with them at all times; sometimes, the only personal belonging of a weak child is a toothbrush; clothes are often shared with other children · Adults usually have a bedside table or a locker, the number of their personal belongings vary according to how active they're perceived to be; legally capable adults have lots of personal belongings, including televisions and laptops · Residents' private space is often invaded by staff without their permission · Toilet cubicles have no doors; there are no rooms where residents can remain alone if they wish 	<ul style="list-style-type: none"> · For active residents, volunteers try to respect their private space and do not touch their belongings without permission; they teach them to treat their intimate spaces according to cultural norms (for example, that it is not appropriate to visit the toilet while others watch) · Volunteers bring residents small presents, such as toys, CDs or clothes, to help them create a personal space

Aspect of construction	Staff views and institutional settings	Volunteers' ideology and practice
Social needs: communication, education, work, entertainment	<ul style="list-style-type: none"> · Bedridden and weak residents are considered to need only feeding and basic hygiene, and of being incapable of human communication and uneducable · More physically active and intellectually able residents can be taught to care for themselves and for others; they help nurses in their everyday routines · School education is considered necessary only for children with mild intellectual disabilities who can talk · Most active and physically strong adult residents work all day long for the institution; for this, they receive small privileges, but no money · Legally capable and physically able adult residents are allowed to leave the institution, visit nearby cafes or shops and drink alcohol 	<ul style="list-style-type: none"> · Volunteers consider school education necessary for all children, regardless of their mental ability; they use methods of alternative and augmented communication with residents who do not use verbal speech · They think that human communication is possible for all people with mental disabilities, even for those with severe intellectual disabilities; they object to staff referring to such clients as "vegetables" · Volunteers often take children and adult residents out of the institutions for picnics, theatre trips or to attend church · The NGO organized educational facilities including a computer class, cooking class, art studio and a carpenter's workshop, and created paid workplaces within the adult institution for residents
Conceptualization and treatment of undesirable behaviour and mental illness/deficiency	<ul style="list-style-type: none"> · All undesirable behaviour (e.g. hysterical behaviour, self-aggression, stereotypy) that is commonplace among the residents of mental institutions is considered an intrinsic attribute of mental illness and deficiency; residents exhibiting any type of undesirable behaviour, either physiological or triggered by certain social situations, undergo so-called psychiatric treatment, including an involuntary sedative injection or pill or being admitted to the psychiatric hospital 	<ul style="list-style-type: none"> · Volunteers mostly view undesirable behaviour as resulting from deprivation and a symptom of hospitalism; they tend to treat so-called hysteria as a natural outcome of emotions provoked by a difficult or unpleasant social interaction involving the resident; they disapprove of excessive use of sedative drugs and hospitalization in psychiatric wards, as practiced by medical staff; they view the diagnosis of mental retardation in some residents as a result of the social conditions they live in, and not as the outcome of organic pathology

their access to legal rights and freedom of choice. For each category of residents, their physical and social needs are interpreted differently by the two types of care-workers. Table 1 illustrates some aspects of the social construction of disability based on the different perspectives of institution staff and volunteers.

Specialized care institutions for people with mental disabilities in the Russian Federation have characteristics of the so-called total institutions described by Goffman (6), such as constant privacy violations, pervasive control over patient behaviour and exploitation of patient labour (i.e. patients work for and within the institution and are paid in small symbolic privileges instead of a monetary reward or salary) All daily activities inside the institutions follow a rigid schedule and everyday life is substantially regulated by and subject to official rules, hygiene standards and safety standards, among others. Thus,

for instance, according to the rules, patients' diapers must be changed three times a day, but some members of staff do this only once. This failure can be partly explained by a shortage of staff and partly by their symbolic attitude towards the ill body (which is considered not quite human) and the ill mind (which cannot distinguish between physical conditions). These attitudes serve to explain the nurses' desire to economize their physical and temporal resources.

The organization of the institution itself reflects attitudes towards the needs and potentials of its residents. The state social policy means that people with quite differing abilities and disorders are crowded together under a single roof, and may thus be perceived as equivalent. However, Table 1 shows that that does not mean that the needs, potentials and perspectives of the patients are not differentiated within the routines of the institution – some patients

are given more freedom (i.e. allowed access to alcohol and have a sex life), while others are given only limited care (hurried feeding and bathing).

Although institution staff classify patients into different categories, this is usually done within the framework of the traditional paternalistic ideology of the state system of care for people with disabilities and of modern Russian culture as a whole. In their discourse and practices, staff of the institution implement the medical model of disability by judging patients first and foremost by reference to their pathologies, defects and medical diagnoses. In western Europe and North America, this was accepted as a self-evident model of disability until the 1960s to 1970s, when it started to be challenged by psychiatrists, social scientists and disability rights activists.

Volunteers follow the ideology of normalization and integration of people with disabilities by challenging the exclusion they face in the Russian society (for the formulation of the principles of normalization ideology, see Nirje (32)). They implement the social model of disability, which states that the limitations of a person with impairments are not the direct result of their impairments (for more information on the disability models, see Shakespeare (33)). Instead, they are caused by failure of the environment to adjust to the needs of the individual, and the limitations are imposed by society in the form of stigmatization and exclusion.

In line with the ideology of normalization, volunteers consider that people with disabilities, even those with the most severe disabilities, should not be excluded from the cultural practices of other members of society. More active residents may be involved in a wide range of cultural practices, from gender display to accessing paid work (see Table 1). For the weakest (for instance, those who cannot move or sit), normalization involves changing the position of their bodies in the morning to symbolize standing up, as performed by ordinary people every day.

The problem with the normalization perspective is that it is not easy to estimate objectively the needs and abilities of patients with severe mental and multiple disabilities. Thus, according to the ideology of normalization, such patients might be included in cultural practices, the meaning and benefits of which

they do not understand. For example, a birthday picnic may be arranged for a deaf-and-blind girl with severe mental retardation, who does not understand what a birthday is and has an epileptic seizure after being exposed to the sun. Even so, the patient has been included in the cultural practice of celebrating her birthday, which makes her seem more human in the eyes of institution staff and volunteers.

Since the field research was conducted, psychoneurological residential institutions and specialized children's homes have undergone numerous changes and are drifting slowly towards using normalization principles. For example, people in the institutions in St Petersburg now have better access to drinking-water. Further, owing to the NGO lobby, children's home residents who were previously considered uneducable now have access to education through being accepted into a public school for children with intellectual disabilities. The number of patients in each ward of the institution has now decreased to 4–7 people. The total number of residents in the children's home under study has decreased from 500 to 350 children. Five children with multiple intellectual disabilities have been adopted – mostly by former volunteers. Families in the Russian Federation are becoming more likely to adopt children with disabilities and more reluctant to place a child born with disabilities into an institution. In big cities, there is a growing network of NGOs and state-run organizations providing support for families with children with mental disabilities. About 10 of the more active residents have left the adult institution and now live in their own apartments or in assisted-living facilities serviced by the NGO. The institutions themselves are more likely to create workplaces and rehabilitation centres for their residents, although deinstitutionalization is still encouraged and initiated by NGOs and disability rights activists.

DISCUSSION

As shown in the previous section, the logic of the internal organization of specialized care institutions for people with disabilities does not provide scope for implementing normalization principles. The policy of the NGO described in this paper is to influence the dominant ideology and practices found in state-run institutions in the Russian Federation. It is creating

suitable conditions for gradually deinstitutionalizing people with disabilities according to western European and North American social policy patterns, and is beginning to incorporate aspects of normalization into the institutions.

Although state social policy-makers now declare the deinstitutionalization vector a priority at the level of official rhetoric, the authorities responsible for developing these social policy reforms have not yet made significant steps in implementing these declarations. This is partly due to the powerful influence of officials and administrative staff of the institution who control the financial resources allocated to the institutions. The efforts of NGOs are not always welcomed by administrators of the institutions. Volunteers may be seen as unwanted inspectors to monitor the abuse of patients by staff and take symbolic control of the patients.

The two contradictory ideologies implemented in everyday practice at residential institutions for citizens labelled as mentally disabled highlight the current changes in public discourse, cultural attitudes and social policy towards people with disabilities witnessed in the Russian Federation today. In fact, residents of the institutions have become a battleground between the two communities of care-workers described (i.e. staff of the state-run institutions and NGO members) in a battle for control over the system of care for people with disabilities and the social policy towards them.

Throughout the history of Western civilization, there have been different attitudes to disability and mental illness, including the eugenic approach (with a social policy aimed at eliminating so-called defective individuals) or isolating people with disabilities in specialized institutions. Since the mid-20th century, Western civilization has broadened the limits of cultural assumptions about normality by encouraging positive discrimination of people with mental or physical disabilities, and enabling the survival and socialization of people with various kinds of disabilities. Methods of augmentative and alternative communication make interaction and education possible, even in cases of severe multiple disabilities, which was unthinkable until recently. People with intellectual disabilities have become fully-fledged members of therapeutic communities, providing an

opportunity for them to have a meaningful existence and to provide useful labour within the framework of post-industrial labour ideology, and thus an increasing role in society. A wider range of individuals are now considered socially acceptable. Today, we witness the process of creating a new normal for people with mental disabilities to challenge the cultural notions of norm, normality and humanness.

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