The Institutional Conditions of the Life of People with Intellectual Disabilities (ID) in a Residential Care Facility

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Abstract: The paper is intended to show a system of institutional care for people with intellectual disabilities, which is characterized by a kind of ambivalence. The whole disquisition is based on two fundamental and dichotomous categories: control and subordination versus autonomy and independence. Each of these categories is connected with one of two perspectives within which a residential care facility can be captured. The first one arises from Goffman's vision of a total institution, where a unit is presented as an objectified subject of other people's actions, revealing a situation of isolation and personal dependence. The second perspective presents a model of relationships between the personnel and their charges; it is characterized by an individualistic approach toward the needs of people with disabilities regarding their right to autonomy and self-determination. The confrontation between these two perspectives and areas of issues is discussed in this paper.

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Background

At the beginning of the 21st century, there was a gradual reform of the entire social welfare system in Poland. For this reason, the last two decades saw increased efforts to modernize and upgrade, but also to restructure institutional aid. This should involve shifting the center of gravity in the functioning of care facilities from places of medical care provision, where the main focus is on the health and physical safety of the residents, to people's needs, viewed from a wider perspective, which relate to both the psychosocial sphere and the emotions and feelings of the residents. These changes were directed toward "normalizing" the life of residents, with the idea of bringing the conditions of individuals' lives in a welfare institution closer to family life.

In this light, the aim of this analysis is to confront the assumptions and expected results of the reforms described above with their actual effects. I do this by referring to studies carried out in the community of staff and residents with ID of care facilities. It seems that although there are now significant changes in the organization and operation of such facilities, they still have many characteristics of a total institution. From an institutional perspective, we are dealing with a model of strong subordination and dependence. All of this makes a residential care facility fit into the scheme of a total institution, which Goffman (1961) describes as social hybrids, combining elements of community with elements of formal organization. They are facilities of a forced transformation of personality. Each of them experiments with the reality, usually in a brutal manner, to prove what can be done with humans.

As the employees of welfare facilities are the direct executors of state policy regarding the provision of help to clients with various intellectual and psychological disorders, the real character of these relationships is influenced by the engagement, skills, abilities, and education of the personnel (DuBois and Miley 2011). In this article, I attempt to show the state and outcome of the previously-mentioned reforms, and indicate the degree to which they have been implemented. To do this, one needs to present a complete picture of the relationship between the staff and care facilities in their dimension of subordination–autonomy. Thus, I will consider external (formal) and internal (institutional) factors, as well as the attitudes of the employees to people with ID.

Review of research

The literature highlights the need for support when public services are provided both in private homes (Harris, Beringer, and Fletcher 2016) and in appropriate institutions providing stationary care (Dunn, Clare, and Holland 2010). Most research focuses on the conditions and the quality of life of people with ID, and to a lesser extent on the contents of the services offered. Therefore, there is a need to put more emphasis on how the staff of different institutions involved in the care and assistance of people with ID negotiate the complexity of risk management and promote autonomy in their daily practice (Björnsdóttir, Stefánsdóttir, and Stefánsdóttir 2015).

Historically, people with ID have not been able to express their autonomy for a long time. People with ID lacked voice, authority, and control over their lives. They were not allowed to make their own choices because of the view that they would not be able to take care of themselves because of their disability (Carlson 2010). Only recently have people with ID been recognized as important contributors to discussions on ID (Wahmsley and

Johnson 2003). Over time, with the development of new currents and models in disability studies, more and more importance began to be attached to the issue of the social inclusion and normalization of life for people with ID, as well as their support for greater independence, self-determination, and ability to make their own decisions (Hoole and Morgan 2011; Mahone et al. 2011). One of the main principles underlying such a policy is to give people with ID the greatest possible autonomy (Chartres and Brayley 2010). According to Meininger (2001), among other authors, respect for personal autonomy is a central value in public policy documents, which also include the recognition of the autonomy of people with ID. In everyday life, this means that person-oriented planning and action should be the basis for providing social services. This translates into attention being paid to the competences and ethical skills of the individual staff members, as well as their ability to influence the charges and their self-determination. According to Wehmeyer, Abery, Mithaug, and Stancliffe (2003), self-determined behavior refers to actions that can be identified by four basic characteristics: the person acts autonomously, the behaviors are self-regulated, the person initiates and responds to events in a psychologically-empowered manner, and the person acts in a self-realizing manner.

Modern studies on disability emphasize that the autonomy and empowerment of people with ID is an extremely important issue on the road to normalizing their lives (Goodley 2000). This position is strongly underlined in international human rights documents and treaties, and should be a guideline for national legislations of individual countries. This is reflected in the construction of a modern model of assistance and support for people with ID in both community and institutional care.

It is now recognized that staff involved in day-to-day assistance and care activities play an important role in the well-being of people with ID, because they influence their daily decisions and needs. However, there is always the risk that individual employees will reflect stereotypical patterns and act on their projections and subjective beliefs (Dunn et al. 2010). Hence, personal values and individual life experiences take precedence (Dunn, Clare, and Holland 2008) over objective values and standards regarding respect for the independence and self-determination of the residents.

Supporting people with ID can be understood as managing two potentially conflicting responsibilities. On the one hand, there is a duty of care that requires workers to support and protect their guests from potential harm to themselves or danger to others. On the other hand, there is a duty to recognize and promote the residents' autonomy and independence in life (Hawkins, Redley, and Holland 2011). According to Olney (2001), workers often assume that people with serious dysfunctions, such as intellectual disability, are so incapacitated that they are not only unable to function independently (with specific support and as far as possible), but are not even able to identify and express their needs. Also, it appears that employees perceive their interactions with people with ID selectively, i.e. some communications are rewarded with attention, while others are ignored. Brown, Gothelf, Guess, and Lehr (1998) stressed that instead of prescribing and enforcing obedience in dealing with people with ID, it is much better to increase possibilities for their actual choices and autonomy. According to these researchers, people with ID often cannot express their needs not because they cannot do so, but because they have been "disciplined" over the years to be obedient. This is probably the key to how employees exercise power and use their positions, perhaps without even realizing that they do this. Instead, people with ID should be adequately supported in their quest for autonomy, and professionals should see them as competent communication partners, respecting their needs (e.g., Brown et al. 1998). Therefore, an important aspect of the care of people with ID is not only seeking greater involvement in their daily lives by those caring for them, but also teaching the carers respect for understanding the needs of their residents as well as the ability to support the charges' self-determination (Arndt, Konrad, and Test 2006).

Methods

The study that was used to write this article was part of a larger project devoted to showing the process of creating, maintaining, and reconstructing the social order in the context of interpersonal relations between the employees and the residents with ID of a residential care facility.

Characteristics of the field of research

The research material was collected during visits to residential care facilities in central Poland. All facilities operated in the public sector, and they were entities that performed national supportive and care tasks.

Ethical considerations

The participants were assured that all the provided information would be treated with anonymity and confidentiality; pseudonyms are used throughout the article for anonymization purposes (Saunders, Kitzinger, and Kitzinger 2014; 2015). All quotations contain the participants' own words. Every interview was audio-recorded and transcribed verbatim. The interviews were held in the Polish language; fragments of transcripts were then translated into English for the purposes of this article (own translation).

Data collection

The material for analysis embraced a total of 52 records from observations as well as 52 unstructured interviewswhich 32 were with personnel (and people from outside the residential care facility, hired in the center) and 20 such interviews with residents (of various levels of disability). The research covered both the charges (with various levels of intellectual and physical disability) and the personnel (including guardians, porters, social workers, nurses, therapists, and physiotherapists). Organizing the research in this way ensured data from various sources; this way, it was possible to compare cases with each other.

Data analysis

Data analysis was an iterative constant comparative process involving descriptive and interpretive analysis (Patton 2001). Both the analysis and the interpretation of the research material were conducted in compliance with the principles of grounded theory methodology (GTM) (Glaser and Strauss 1967; Glaser 1978; Strauss and Corbin 1990; Charmaz 2006). Hence, the selection of subsequent cases for the research was of a theoretical character (ang. *theoretical sampling*) based on the constant comparative method. The work on the analytical and conceptual level was performed with the use of the NVivo program (Lonkila 1995; Richards 2005 Wiltshier 2011).

Assurance of quality

I followed Lincoln and Guba's (1985) principles of trustworthiness as well as Charmaz's (2006) validity guidelines for grounded theory. Theoretical saturation, the constant comparative analysis, trustworthiness, and validity checks all assured data quality and rigor.

Findings

A residential care facility is both a workplace for its staff and the space of daily existence for its residents. Thus, it is where two extremely different subworlds must coexist, forced to build one common organism. A residential care facility is a unique place where residents can realize the concept of self-determination, but it is also where their autonomy and freedom of action is limited. This limitation may be evaluated ambiguously. Despite the fact that it arises from the willingness of the people with disability to subordinate themselves to the control of the personnel, it is also performed with the consideration of the well-being of the charges themselves, who are not always able to take proper care of themselves.

Planes of control versus autonomy in residential care facilities

In both institutional and interpersonal dimensions, residents' lives as well as the work of the staff, are determined by the scope of acceptable control of the staff of the care facilities *and* the autonomy that the residents themselves can achieve. In this paper, these two dimensions are confronted at the level of managing time and space as well as at the level of the body and the sphere of the residents' corporeality.

Space and time

Space organizes the interpersonal relations between the residents and the staff of a residential care facility. The space is symbolically constructed in the course of social interaction between these two groups. How it is understood and determined will greatly depend on the social context of the actors within the interaction. In some sense, the space creates the context of the actors' activity, providing their actions with meaning, establishing interactional order, and triggering mechanisms that construct the institutional order. Space, like other aspects of life, also undergoes the process of taming and adapting by both the charges and the employees. The personnel work on the interpretation and meaning of the space in the context of performing supportive actions. Rationalizing the existing dichotomies between the two dimensions of the space – i.e. the workplace of the personnel and the living space of the charges – constitutes one of the basic elements in the process of professional socialization and the professionalization of a new worker's work. As far as the resident is concerned, the problem of adapting to the facility is connected with taking steps aimed at protecting the possessed and obtainable spatial independence from the personnel (based on the resident's psychophysical abilities).

> They approach us all the time; they try to take something more out of us. Sometimes it's a specific thing, let's say a simple candy, and sometimes they just want to come to us and sit for a while. But it's like, when one comes inside, and we let them, another one wants to come as well. They sometimes argue about it. We try to be careful, but it's sometimes impossible. (a nurse)

A significant division is the differentiation between *interpersonal* space and *structural* space, which also serves to categorize the space. The former one refers to interpersonal relationships between social actors. It determines the boundaries of physical closeness and the emotional engagement of the personnel, i.e.

the scope and character of their contacts with the residents. The relationships might be direct, encroaching on the personnel's private sphere. However, they can also be specified with a cautious attitude of the guardians, or (mental) isolation from the residents (as far as it is possible). Hence, the workers may decrease the spatial distance. Conversely, they might shield themselves from close contact with the charges, thereby creating the corresponding emotional atmosphere in the facility.

> When they come to sit with us, it's ok. But they also want to use it then, because they must think that if we allow them to sit here, then we'll also allow them to do other things. And since they are with us, they'll play up to us, and it actually happens that we do what they want. It's like that saying, "what the eye does not see, the heart does not grieve over." (a social worker)

The closer the interpersonal relationships between the personnel and the charges, the smaller the distance in the structural dimension between the two groups. The structural dimension of space can be divided into several basic subcategories (Goffman 1979). They include "open spaces" – always available for the charges, with some exceptions (e.g. rooms, bedrooms); "semi-open spaces" – with common access, but limited to daytime or particular moments in the resident's life (e.g. rooms for therapy and rehabilitation); and "closed spaces" – always out of bounds (e.g. facilities with medicaments).In the structural dimension, there is also a possibility to divide the space into "available," "unavailable," and "common." This refers to the situation and factors that characterize the person with ID, e.g. health, degree of disability, etc. In such a case, the availability is not decided by the personnel, but by the individual features of each charge.

> It depends on the person. Those more capable have more possibilities than those who are bedridden. We try to help everyone, but our number is limited. So, when a resident is relatively independent, it's easier for them to move, so they can do more things then. (a therapist)

The space organizes the interpersonal relations and supports the process of agreeing on the definition of the situation between the residents and the staff of the nursing home. Furthermore, the availability of the space is also correlated with the temporal dimension of life in a residential care facility, e.g. depending on the season, some spaces become unavailable (including the facility's exits for people with more severe physical dysfunctions). In other words, the order of the space's availability is also conditioned by the temporal dimension of the charges' institutional life.

Apart from the availability of space, a factor that determines how the life of the residents is constituted is how time is organized. There is a clear rationing of time devoted to particular actions, which is connected with how the day is divided. The most significant points in planning a day in a residential care facility include those connected with fulfilling basic needs, e.g. sleep, meals, or physiological needs. The possibility of fulfilling "higher-level" needs recedes into the background.

It is worth underlining that almost all of the residents' life events become subjected to schematic reproduction. Thus, a conformist attitude of the charges is constructed, which creates conditions for the surveillance and control over the residents. Which activities will be performed when depends on the day plan imposed on the charges. In this respect, the resident is left with no choice.

> We know when the time of the canteen fund and shopping is getting closer, there's a lot of fuss then. But also, after the shopping, when they get the donuts, then there's this hullabaloo. We've been doing it for a while, so we know what to expect then. (a social worker)

The category of "awaiting" is also inscribed in the temporal perspective of the actors' actions. Usually, this is waiting for something that can – or, according to those waiting, *will* – happen in the future. However, neither the aim nor the time when it is to be fulfilled need to be precisely specified. In a residential care facility, the category of awaiting is understood differently, depending on whether it corresponds to the personnel or the charges. For the personnel, the time perspective is usually "closed," meaning that the target point of carrying out the tasks is determined and, possibly, entirely predictable, and the aim is particularized. On the other hand, the perspective of the time of awaiting by the charges is "open," which means that it is hard or even impossible to specify when the aim will be fulfilled. The aim itself is somewhat unreal and hard to fulfil.

> Even if I wanted to, I can't do many things with them, because I don't have such legitimation, or this is what the regulations say, or you can't do it because they have their limitations, and so that's that. Another thing is that they sometimes have ideas, but it still changes a lot. Of course, I'm happy when I can communicate with them and find out what they want directly, but they are often rather unreal expectations. (a nurse)

The space and time are different for the workers and the charges. Both dimensions of the existence of people with a disability, as well as their limited autonomy, may become an element of both control over the residents' lives and their subordination to the personnel of the facility.

Body and the problem of its integrity

In a residential care facility for individuals with intellectual disability, two main notions need to be settled – first, to what extent the body of a resident is subjected to their own will and is actually controlled by them, and, second, to what degree their body may be interfered with by other people (Charmaz 2019). The personnel perform care procedures and assess the physical condition of their charge. The body undergoes various procedures; it becomes an integral part of the professional activity of the personnel.

> Yeah, this is the bath time that I remember the best. My friend and I came on 1st February, God I can't remember anymore, and on the second day we went to the bath, and we saw several dozen naked men. Because then there was this group washing, there were showers downstairs. So, it looked like that. And I performed this bath time together with my friend. There was also a guardian, or a helper, I can't remember anymore. We gave out the clothes, and the residents were washing themselves. (a nurse)

In a residential care facility, a resident's body is subjected to top-down requirements. The same body is trained and grasped in accordance with the expectations of the institution, and then controlled, whether it meets these requirements or not. The body stops being a private space of the resident; it becomes "published" in various contexts and situations. Sharing the space with other residents means that any intimate care procedures are performed in the presence of other people. From this perspective, the bodies of the charges, as well as the staff themselves, undergo a certain form of "taming." At the same time, one can observe the process of "forgetting" about the feelings of shame and intimacy, which degrade gradually. The residents' privacy is not only minimized; their most intimate situations are even exposed. It also applies directly to the resident's sexuality. In this case, and officially for health reasons, the personnel attempt to prevent uncontrolled sexual behaviors. However, at the same time, in informal conversations, as a reason for their supervisory actions, they are an area of "concern" about their charges' "personal interests."

Thus, the personnel's attitude toward the problems of their charges' sexualityincorporatesan ambivalent shape. On the one hand, they put the well-being of the charge first. On the other, perceptions of the charges' sexuality are conditioned by a concern about the potential consequences of the charges' sexual activity, not only for themselves, but also for the employees.

> I mean, it's generally hard to discuss stuff like this, because they have a right to the same things as others. And they have their needs, too. The fact that they're sick doesn't mean that their needs are eliminated. It's a natural order of things. But we also take responsibility for them, and we can't allow such situations. If anything happened, and if it resulted in something, we'd have a serious problem, I think. (head of the social department)

This ambivalence of sexual attitudes is not only limited to the problems of denying the charges' sexuality, but it also refers to informally allowing the residents' sexual behaviors. Therefore, there is a kind of game of preserving appearances and not seeing the problem, and there is a common "quiet permission" of personnel, doctors, and psychologists to these sexual behaviors. In the official discourse, in the formal framework of conversations between experts in a given field, such notions are rarely encountered, but they are entangled in less official discussions.

Official actions of the personnel toward sexual (with oneself) and homosexual behaviors of the charges are most often directed at eliminating those behaviors by offering various forms of physical activity, and often pharmacological treatment. A less official approach to the notion of the residents' sexuality is expressed by a member of staff:

> (...) it's ok as long as they're not heterosexual relations. (...) a scandal begins when there is something between them, i.e. men and women. But when two men indulge each other, it's the least of our worries; there won't be any children out of that *[laughter – note by author].* (a therapist)

The body is also a form of expression and a space for the residents to articulate themselves. Therefore, what a resident consciously does with their body, and how they do it, is a symptom of what they currently need, lack, or expect from the environment, thus signalling specific needs. Hence, the residents are not completely deprived of the chance to create messages through their bodies, and not only in accordance with their intentions, but also in order to manipulate others (e.g. faking politeness). Manipulating the body is an attempt to obtain living space and expand the scope of their autonomy.

Therefore, the corporeality of a person with disability can be looked at from two perspectives. The first one relates to natural and uncontrolled physiological reactions, independent of the person with disability. They include any kind of stereotyped movements, reflections, but also limited control over the basic physical processes and physiological needs. The second perspective refers to the body as a space for the resident's actions. They "use" their corporeality as a tool which they control and through which they have a certain power over the environment. It is a relatively "fragile" power, based on triggered emotions of the staff (e.g., empathy or compassion) and their "weakness" toward the charges (e.g. the fact of being a favorite). It also evokes certain affective states in the personnel and might include actions that lean toward misleading the personnel or which hide the resident's actual emotional state (e.g.simulating malaise to avoid certain responsibilities).

Between control and autonomy – the ambivalence of principles and values

Referring to the nomenclature of Erving Goffman (1967), in a residential care facility, we can differentiate two kinds of relationships between the main actors of interactions, namely symmetrical and asymmetrical relations. The former refer to situations when both parties are equal in rights and duties. The latter constitutes a contradiction of such an equality. Because in a welfare facility there are two main categories of social actors – i.e. the personnel and the charges – the symmetry–asymmetry dependency between the two groups can be presented in a simplified form. People incorporated in the same environment are in a symmetrical relationship with one another (i.e. personnel with personnel, residents with residents). Taking a closer look at the relationships on the personnel–residents line, one deals with asymmetric relations, i.e. those characterized by an unequal division of power and one-sided dependence. Going deeper into the sphere of relationships between people from those two environments, it can be assumed that there is a dual perspective of independence–subordination, therefore determining the spheres of autonomy and control.

The personnel's power

Although smaller in number, the personnel definitely hold stronger positions than the charges. The whole power is focused in the hands of the workers, and the residents are, in practice, deprived of any possibility to make decisions for themselves. They are subjected to meticulous control in every sphere of their lives. This totalizing character of a welfare institution goes very deeply, covering the private and intimate spheres of their lives as well as emotions and feelings or the sphere of sexuality mentioned before. Even the most protected aspects of the individuals' existence, such as corporeality and physiological activities, were uncovered and became public in numerous case. Another dimension of a facility's totalizing character is its interference. The relationships between charges and *the external world* are mediated, which means that a person with disability knows only as much about life outside the center as they can get from the personnel (it is also necessary to take into account the general psyche and mental condition of the resident).

> There was no elevator in the past; there were no beds with wheels. This facility was more closed in the past, and, for example, people who were bedridden, less capable, did not go outside, right? Because there was no such possibility *[raised voice – note by the author]*. Only the head created such a possibility, so we started to take them out, right? (a therapy leader)

Referring to the concept of a total institution, it can be concluded that the charges are somehow enslaved and subjected to the actions of third parties without any influence on their own life and fate. Although it significantly overlaps with my observations, it would be wrong to state that the power and control that the personnel have over the residents is practically unlimited. Among the limitations of permanent control are those that relate to personal and institutional determinants, including the formal rules and standards to which employees must adhere. Thus, the power that they are subjected to needs to be properly controlled and limited to the minimum that is necessary to fulfill support and welfare functions and tasks. Therefore, it comes down to the level of control that will allow the organization to function properly and enable employees to carry out tasks with minimal discomfort for the residents.

> We don't use any direct force, only the prescribed medicines, which may be taken by the residents under the doctor's control. There are no stripes or straitjackets, or even more serious pharmacological preparations which hospitals have, no. There's a doctor every day, so ... itonly involves observations, and in conversation, because you can deduce a lot from a conversation. (a nurse)

At the same time, there are the so-called *internal brakes*, which are based on the emotions and feelings of the staff who take care of the residents. Also, in connection with empathy, ethics, and the feeling of morality, they draw boundaries of permissible interference in – and control over – the charges' lives.

> It's hard to force our residents to do even what is good for them. They simply don't want to do a lot of things. But it gives you nothing if they do it by force. (...) And I don't have the heart to forbid them anything that gives them pleasure, for example. (a therapist)

A general principle that theoretically applies to the members of staff is that control must not harm or be bothersome for the charges. However, it needs to serve them by protecting their lives and health against their actions as well as the behaviors of the other people with disability. The aspect of providing control and life protection is one of the motives to rationalize control over the charges. Power and control are held for the "good" of the residents, and they are essential to carry out basic care and welfare tasks.

> We supervise, so it's quiet and no one harms themselves. Maybe they'll dream about something; maybe they'll start sleepwalking and jump from the second floor. So, we're here at night to watch them, supervise them, so nothing bad happens to them. So, when he walks away, we don't know if he is going to the toilet or for a cigarette, or if he feels bad, or maybe he'll fall down in a minute, or vomit somewhere in the bathroom. You need to have the eyes at the back of your head. (a nurse)

Therefore, the control has two faces here; one totalizes and appropriates the subjectivity of an individual, while the second one is connected with the responsibility that the personnel bear for their mentally-handicapped charges. Control and responsibility create a closed system, directly influencing the interpersonal relationships between the personnel and the charges. By assuming the role of a supervisor with a wide range of control over a resident, the staff take on more than just a burden of responsibility.

Opportunities and areas of self-determination for the residents

At the same time, the situation of the people with disability depends not only on the formal regulations of the welfare institution, but also on the personnel who follow those rules. The residents are not totally without influence on their fate and the protection of their own rights and freedoms. Their role does not finish with a passive and fatalistic approach that focuses on awaiting help and understanding from the workers. It needs to be stated that despite the interference of the personnel in the charges' lives, aperson with disability has the right to decide about and determine their own lives.

> They're bossy in their own ways – they don't allow you to hurt them. They are aware that they're in the majority, which is good for them, and they take care of it. Let's take Agatka, for example. She can do it by herself, and she wants to clean on her own, arrange her things as she wants to. And even if it's not great, she does it on her own, and she's happy with it. And when you try to move something, she immediately gets upset and angry. So, I'm happy that it's this way. She's happy, and I've got no trouble. (a nurse)

The sphere of *autonomizing* the life of the residents of a residential care facility includes respecting the willingness of the charges, e.g. taking part in therapy or other activities. As emphasized by the employees of the facility, in such situations *"it is better to provide them with an opportunity to choose, (...) they need to want to come to us, you cannot force them."* This means the personnel (especially the therapists, teachers, and physiotherapists) are orientated toward the residents' freedom regarding making choices and how they participate in proposed activities. An element of the residents' self-determination – managing a certain sum of money, i.e. the so-called economy training – is also inscribed in the therapy framework.

> The residents have their money. That is, they have their sub-accounts where this money is collected. If a resident is incapacitated, then we, i.e. the legal guardians *[sometimes the family – note by the author]*, administer the money. But if a resident is not incapacitated, then they can spend this money as they want to. We try to make sure they don't spend this money on something stupid, and we ration these funds a little, otherwise they'd spent the whole amount on the first day. But this is their money, and they have the right to it. (a social worker)

At the same time, the personnel tries to provide the residents with a certain level of privacy and the feeling of independence, including the possibility to create their own space, to *domesticate* and *tame* it, where they can place their private things. Therefore, it is a possibility to possess their own items and to make decisions about them.

> I can hide everything here *[the resident points to her cabinet – note by the author]*. No one will rummage there. When it was another way, they ate my sweets and took away my sugar. (a resident)

Another form of autonomy is enabling the residents to freely choose with which other residents they establish certain bonds based on emotions and feelings (including friendship). In practice, it means they can satisfy their need for closeness and interpersonal contacts; however, this is also rationed in some circumstances. It happens when the workers – "for the good of the charges," as they put it – monitor relations between the residents and, if necessary, they limit those relations which are undesired for various reasons, or which might be dangerous, according to the workers. Such actions produce mixed feelings in terms of control over the charges and their independence. No one can tell the residents whom they should like or avoid; however, the personnel can use various measures, e.g. moving charges to different rooms within the facility if the relationships between the residents are not in line with the intentions of workers. It means that the *choice* and *match* of thepeople with disability toward each other greatly depends on the workers.

> We want our residents to understand each other. And when there are friendships among them, we support it. But if there are any problems, we need to intervene. For example, recently, we needed to separate Malwina from Jagoda, because although they were such good friends, they fell out about something and one started attacking the other. And it didn't suggest anything good. We'll see when they calm down. (a psychologist)

Free movement constitutes another form of autonomizing the charges' lives. However, in this case, we also deal with situations that might provoke mixed feelings. On the one hand, the residents can move freely in the facility, but on the other hand, it is possible only within limits which are strictly determined by the personnel. What is more, it needs to be borne in mind that rationing the space is one of the ways to control the charges, and it is reflected in the principles that govern a total institution.

> You may try to control them, I mean to be careful about what they do, but you can't force them to do what you want. You need to understand it, because there are people who need some intimacy, as we do. You can't impose everything on them, because they have their rights and they can also decide about some things. (a manager of social workers)

Therefore, when considering matters of the residents' freedom of movement, one must take into account numerous interconnected limitations. They are conditioned by the unique principles that exist in the facility, as well as by the residents' skills.

Discussion

In the context of, on the one hand, picturing the control and surveillance system in a residential care facility, and, on the other, stressing the need to implement the concept of an individual's subjectivity and self-determination, it is worth taking a closer look at the situation of those - people withintellectual disability who reside in such facilities. It is particularly relevant in light of Poland having a long history of discussion between the supporters and the opponents of institutional forms of aid (Granosik 2006). However, this is not only a problem in Poland, as these issues are also considered by researchers and care practitioners in other countries (Bekkema et al. 2015; Geniene and Sumskiene 2016; Kelly et al. 2019; Klepikova 2019).

My research does not give an unambiguous answer as to which aspect of life in a residential care facility dominates – control-supervisory or subject-independent? Taking into account all the notions presented above, a relatively mixed picture emerges, i.e. one where elements of segregation and integration, which are components of a total institution, along with concepts of the residents' subjectivity and autonomy, are entangled. To a certain extent, they improve the situation of the residents, but they do not eliminate the consequences of subjecting them to the requirements of a welfare institution. It is still an "uneven fight of forces," where the people with intellectual disability (ID) are the weaker side (Barnes and Mercer 2003). Therefore, in numerous cases, some residents associate welfare homes with hostile places, full of constraint, almost complete dependence, and deep control (cf. Shakespeare 1996). Thus, it is necessary to prevent the negative effects of placing a person with disability in a welfare home (Gonzalez-Rodriguez and Fernandez 2017). Activities aimed at this largely depend on the staff, because, in order to develop positive interactions with the residents, it is necessary to create a suitable atmosphere and a sense of well-being for them, i.e. that they feel cared for. At the same time, however, they are given a certain amount of independence and autonomy. In these institutions, preserving subjectivity is important, although it is exceedingly difficult in a sizeable hermetic community. It means that showing respect and caring about the dignity of all people, regardless of their situation, health condition, or degree of retardation, is a significant aspect of educational and care work (DuBois and Miley 2011).

The literature repeatedly stresses that the basis for practicing care work is the professional relationship created between the staff and the patient (Marsland, Oakes, and White 2015; Trip et al. 2016). These issues also need to be considered more broadly, as not only carers but also medical care providers (doctors) need to have an adequate understanding of people with ID, as shown by the research conducted by Lennox, Diggins, and Ugoni (1997) or Crocker (1988), among others.

It should, therefore, be the responsibility of the staff to neutralize the effects of the stay in the facility, including the control and dependency of the residents. However, as suggested by the outcomes of my research, in a residential care facility, we are dealing with the process of "standardizing" control, i.e. inscribing it somehow into the canon of ordinary actions while carrying out tasks (Sumskiene and Orlova 2015).

To sum up, it can be concluded that the control that is present in a welfare home is inscribed in the main trend of personnel's actions, and it seems that it constitutes an indispensable element of their professional actions. Hence, the life of an individual with disability in a welfare center becomes marked by a particular regime of orders and prohibitions, with equally deep and profoundly specified sanctions for not following them. Although there are vastly different ways of neutralizing the burden of control – which should be facilitated by new legislative solutions and by structural and organizational changes – it remains one of the key features that make it possible to qualify such places as totalizing institutions.

Concluding remarks

The matters discussed in this paper provide information on the social relationships in a residential facility, their dynamics, and the tensions that accompany the personnel and the charges. All of the presented notions constitute a source of knowledge about the behaviors and actions of residents with intellectual disability of a welfare facility as well as the personnel. However, they make it possible to take a look at the relations between the personnel and the residents from the perspective of working on interpersonal relationships. In the case of the charges, it is about making attempts to obtain or expand their autonomy and independence from the personnel; and in the case of the employees, it refers to preserving their control over the residents and counteracting potential situations that endanger the developed and trusted work schemes. In other words, there is a balance between control and autonomy, independence, and subordination, all of which remain in constant but dynamic balance. Hence, it is a crucial element of the personnel's work as well as a considerable dimension of interaction order in a residential care facility. The scope and character of this autonomy and independence of the residents may seem quite modest. This is because what the residents of a residential care facility desire the most – and what is, at the same time, hard to achieve – for most of us is a natural and virtually unseen element of everyday life. The range of possibilities regarding independence is limited by the institution and the people that are employed in it, as well as the level of mental and physical dysfunctions of the residents themselves. In other words, what is available for most people without any effort may be the peak of the individuals' with disability abilities in the circumstances presented herein – everyday choices, freedom of movement, and relative independence when performing basic tasks. However, this does not mean that there are no opportunities to develop the residents' with disability individualism or to treat them subjectively. To some extent, their otherness is honored here, and there is the possibility for every resident to carry out their wishes as far as their mental, and physical abilities allow it.

Summing up, realizing the concept of subjectivity in a residential care facility involves constant negotiations between the personnel and the residents, which occur while making the residents autonomous and independent, although the omnipresent, totalizing control and subordination of the person with disability is still present. The limitations introduced by living in a care institution may, to some extent, be leveled by the personnel. Through the workers' actions, they are able to create conditions that support the development of the subjectivity ofa person with disability. Therefore, the abilities and engagement of the personnel, but also the possibilities of the charges themselves, are components in the process of developing an interaction order which significantly modifies the situation of a person with ID, providing them with an opportunity to express their own humanity despite the not always advantageous institutional conditions.

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Instytucjonalne uwarunkowania życia osób z niepełnosprawnością intelektualną zamieszkujących domy pomocy społecznej w Polsce

Abstrakt: Celem artykułu jest ukazanie, charakteryzującego się swoistą ambiwalencją, systemu instytucjonalnej opieki nad osobami z niepełnosprawnością intelektualną w Polsce. Cały wywód opiera się na dwóch zasadniczych i dychotomicznych kategoriach: kontroli i podporządkowaniu *versus* autonomii i niezależności. Każda z tych kategorii jest powiązana z jedną z dwóch głównych perspektyw postrzegania domu pomocy społecznej. Pierwszą, wywodzącą się z goffmanowskiej wizji instytucji totalnej, w której jednostkę przedstawia się jako uprzedmiotowiony obiekt działań innych osób, demaskując sytuację izolowania i zależności osobistej. Drugą reprezentuje model relacji personelu i podopiecznych, charakteryzujący się indywidualistycznym podejściem do potrzeb osoby niepełnosprawnej, z poszanowaniem jej prawa do autonomii i samostanowienia. Konfrontacja tych dwóch perspektyw i obszarów zagadnień jest przedmiotem rozważań w niniejszym artykule.

Słowa kluczowe: autonomia, kontrola, dom pomocy społecznej, opieka instytucjonalna, niepełnosprawność intelektualna, relacje interpersonalne