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Experience of deinstitutionalisation from service users' perspective in Croatia

As in other post-socialist countries, the process of deinstitutionalisation in Croatia began much later than in Western countries. A turning point is the year 2014, when the mass relocations of people with intellectual disabilities from long-term institutions to community-based settings began. The focus of this research is on the experiences of deinstitutionalisation from the perspective of service users. The research methodology is based on a qualitative approach because it enables a deeper understanding of the problem and allows the researcher to focus on real life experience of respondents. The sample included 27 participants (14 males, 13 females) who during the research lived in 11 different group homes in different parts of the Republic of Croatia. Based on thematic analyse, the results show that the majority of respondents had to move from a long-term institution to a group home due to necessity when long-term institutions were closed. The criteria by which someone was selected or excluded for admission to the deinstitutionalisation process was his or her functionality (e.g. good behaviour, physical mobility). Finally, the research shows that most participants were not systematically and purposefully prepared for the transition from a long-term institution to a group home. Findings of the study are partly in line with the international literature, highlighting the marginal role and difficulties of service users in the deinstitutionalisation process.

Key words: *intellectual disability, relocation, community-based support, group homes, long-term care.*

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Izkušnja deinstitucionalizacije iz perspektive uporabnikov storitev na Hrvaškem

Tako kot v drugih postsocialističnih državah se je proces deinstitucionalizacije tudi na Hrvaškem začel pozneje kot na Zahodu. Odločilno je bilo leto 2014, ko so se začele množične preselitve ljudi z ovirami iz institucij za dolgotrajno oskrbo v skupnostne namestitve. Namen raziskave je ugotoviti izkušnje oseb, ki imajo intelektualne ovire, z deinstitucionalizacijo. Raziskovalna metodologija temelji na kvalitativnem pristopu, ker poglablja razumevanje problema in raziskovalcu omogoča, da se osredotoči na izkušnje respondentov z resničnim življenjem. Opravljeni so bili delno strukturirani intervjuji s 13 udeleženkami in 14 udeleženci iz 11 različnih izvajalcev storitev stanovanjskih skupin na področju Republike Hrvaške. Večina sodelujočih je navedla, da so se iz institucij za dolgotrajno oskrbo preselili v stanovanjske skupine zaradi zaprtja institucij. Merilo, po katerem je bil nekdo sprejet v proces deinstitucionalizacije ali pa zavrnjen, je bila njegova funkcionalnost (npr. lepo vedenje, telesna mobilnost). Raziskava pokaže, da večina sodelujočih ni bila deležna sistematične in namenske priprave na prehod iz institucije za dolgotrajno oskrbo v stanovanjsko skupino. Rezultati raziskave delno sovpadajo z izsledki mednarodne literature, ki prav tako ugotavlja, da so uporabniki v procesu deinstitucionalizacije marginalizirani.

Ključne besede: *intelektualne ovire, preselitev, podpora v skupnosti, stanovanjske skupine, dolgotrajna oskrba.*

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1 Introduction

Deinstitutionalisation[1] is a concept based on different theoretical origins, so there are variety of definitions that emphasise certain aspects (Videmšek and Leskošek, 2015). Essentially, it can be said that the process of deinstitutionalisation does not only mean the closure of long-term institutions, but also the development of services in the community that enable people to live self-determined and independent lives (Videmšek, 2013). This is in line with the values and activities of social work, therefore a mutual intertwining is inevitable (Ramon, 2003).

For example, deinstitutionalisation is embedded in the paradigm of human rights, and advocacy for these rights is one of the methods of social work (Ife, 2012). In addition, social workers manage cases and provide support during the process of community integration, using some inherent methods such as personal planning and risk analysis (Flaker and Rafaelič, 2023).

It is already well documented that long-term placement in total institutions leads to social breakdown of people (Torre, 2021). The experience of abuse and other forms of inappropriate treatment further compromises their dignity (Rafaelič and Flaker, 2021). This is particularly emphasised by the human rights model, as such acts violate the provisions of international documents (Mihanović, 2019). But even before the development of the human rights model, strong opposition to the confinement of people in total institutions was articulated through various approaches such as social psychiatry, anti-psychiatry and the concept of normalisation (Torre, 2021).

Among the most important is the independent living movement, which demanded that people with disabilities receive support that enables them to live in the community like the rest of population (Jolly, 2015). In addition, the concept of self-determination, i.e. control over one's own life, is also an important value in the idea of deinstitutionalisation (Wehmeyer and Bolding 2001).

The theory of deinstitutionalization does not only argue for replacing institutional forms of care with support for community life but presupposes a change in the power relations between »clients« or »residents«, and care professionals, a change in the institutional culture and other aspects (Goffman, 1961; Mansell *et al.*, 2007; Flaker, 2015). Deinstitutionalization therefore requires: redefining the function of service providers, changing the position of service users (residents), ensuring that users have the right to choose their personal lifestyles and also the right to work and financial independence, and the ongoing development of community services (United Nations, 2006; Ministry of Health and Social Welfare, 2010).

These principles have influenced the development of the deinstitutionalisation process, which means a change in attitudes towards people who need

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[1] Deinstitutionalization is often only seen as the process of closing institutions, hence the misunderstanding that it eliminates all the difficulties institutionalization entails (European Expert Group, 2012). To avoid such confusion and better emphasize the multidimensionality of the process, the European Expert Group (2012) proposes the term "transition from institutional care to community support."

a certain kind of support for everyday life, integrated into the wider community (Mansell *et al.*, 2007).

2 Deinstitutionalisation in Croatia: moving from long-term institutions to community-based settings

The realisation of the deinstitutionalisation process is determined to a large extent by numerous social and political forces, so that there are distinct differences between many countries (Šiška and Beadle-Brown, 2022). In Croatia, as in other countries that had socialist systems, the process of deinstitutionalisation is significantly delayed compared to Western countries (Zaviršek, 2017).

The first step toward deinstitutionalization in Croatia was in 1997 when the Association for Promoting Inclusion was founded, today the largest provider of organized housing services. Croatia's legal framework for deinstitutionalization comprises various international documents and national regulations. The most important is the Convention on the Rights of Persons with Disabilities (United Nations, 2006) which the Republic of Croatia, as one the first countries, ratified in 2007 (Korać Graovac and Čulo, 2011).

But, after the ratification of the Convention on the Rights of Persons with Disabilities and the subsequent adoption of fundamental strategic documents, the process finally intensified (Disability Ombudswoman, 2015). However, the most significant is the *Plan for Deinstitutionalization and Transformation of Social Welfare Homes and Other Legal Entities Performing Social Welfare Activities in the Republic of Croatia 2011–2016 (2018)* (the so-called Master Plan; Ministry of Health and Social Welfare, 2010). This strategic document was adopted in 2010 and intended to accelerate deinstitutionalization and transformation.

The plan entails individual analyses of social welfare homes, which follows one of three possible directions: transformation into so-called community service centers, transformation into homes for intensive and long-term social welfare or simply closure. Another important set goal was the development of non-institutional services in proportion to the reduced total number of users in permanent or weekly accommodation. The plan stipulated that social welfare homes develop an individual plan to identify opportunities for transforming the homes. Accordingly, some homes embarked on deinstitutionalization, financed by the relevant Ministry and partly by international organizations.

A turning point was 2014, when the first mass moves of people with intellectual disabilities from long-term institutions to group homes[2] began

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[2] Group homes as a form of support already appeared in the early phases of deinstitutionalisation (Videmšek, 2013). In a group home several people make up a common household and live in a house or apartment within the community (Cocks *et al.*, 2014). In Croatia, group homes exist as a service called "organised housing", provided by state institutions or non-governmental organisations. A maximum of 8 service users can live in one housing unit, who receive a support from a few hours a week to 24 hours a day, depending on their needs.

(Disability Ombudswoman, 2015). There is no exact data on the number of adults with intellectual disabilities who have moved from long-term institutions. However, the existing data shows that 1,847 people were in long-term institutions in 2015. Over the next few years, the number fluctuated, while from 2020 onwards there was a significant increase, mainly due to the increase in the capacity of non-state service providers. According to the latest available data, 2,021 adults with intellectual disabilities were living in long-term institutions in 2022 (Ministry of Labour, Pension System, Family and Social Policy, 2023).

Table 1: Number of users of long-term accommodation – adult persons with intellectual, physical and sensory disabilities.

	2015	2017	2018	2019	2020	2021
Long-term accommodation[3] – state homes	891	855	858	867	841	844
Long-term accommodation – non-state homes	843	619	855	865	855	943
Long-term accommodation – other legal entities	113	114	119	120	123	225
Long-term accommodation – total	1,847	1,588	1,832	1,852	1,819	2,012

Source: Ministry of Labour, Pension System, Family and Social Policy (2023).

Although there was a national plan aimed to reduce institutionalization of people with intellectual disabilities by the year 2016 for 30%, we can observe that there is a constant grow of the population of people with intellectual disability who live in an institution.

Table 2: Number of users of organized housing – adults with intellectual, physical and sensory impairments.

	2015	2017	2018	2019	2020	2021
Organized housing – state homes	259	291	298	316	328	363
Organized housing – non-state homes and other legal entities	406	416	422	441	464	479
Organized housing – all service providers	665	707	720	757	792	842

Source: Ministry of Labour, Pension System, Family and Social Policy (2023).

The data in the Table 2 show that Croatia carries out deinstitutionalization mainly based on the idea of organized housing. From 2015 with 665 people with intellectual disability living in a group homes (state and non-state) the number had been constantly growing as in 2021 there was 842 people with

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[3] The new Social Welfare Act (2022) calls this service only "accommodation", without prefixing the adjective "long-term".

intellectual disability living in a form of group home. But these are mostly people with intellectual disability who did not previously live in an institution and are now accommodated in the newly opened places, only a small part of them are for those who come back to community from institutions. Those who lived in the institution moved intensively only in 2014 and 2015. This means that dispite some people moving, new ones still came to the institutions. Moreover, the number of places in institutions increased after 2020.

3 Moving from a long-term institutional care to a group home

Institutional care has proven to be extremely harmful and limiting in many aspects (Kozma, Mansell and Beadle-Brown, 2009; Johnson and Bagatell, 2020). For example, people living in long-term institutions usually exhibit more aggressiveness, behavioral problems and psychological difficulties with an increased use of psychopharmaceuticals. Their ability to choose where and with whom to live and numerous other human rights are greatly limited (Stancliffe *et al.*, 2011; Murphy and Bantry-White, 2021).

The risk of experiencing abuse is significantly higher compared to living outside institutions (World Health Organization & The World Bank, 2011). Users in total institutions believe that the time spent there has marked their lives negatively. They cite numerous negative experiences related to lack of freedom, feelings of inequality and social uselessness (Hutchinson and Sandvin, 2019).

On the other hand, Pretty, Rapley and Bramston (2002) state that people with intellectual disabilities, who have always lived like the majority of the population in the community, are no different from people without intellectual disabilities regarding neighborhood experiences and various quality of life aspects. Especially important is the finding that people with intellectual disabilities living independently cited significantly fewer (negative) events compared to people living in community group homes and significantly less than those in institutional settings (Myles et al., 2000; Bond *et al.*, 2019; Hastings *et al.*, 2004).

Studies, covered by meta-analyses, have consistently proved that deinstitutionalization brings positive changes in the lives of people with intellectual disabilities (Kim *et al.*, 2001; Kozma, Mansell and Beadle-Brown, 2009; Lemay, 2009; Hamelin *et al.*, 2011; Larson, Lakin and Hill, 2012; McCarron *et al.*, 2019; Bredewold, Hermus and Trappenburg, 2020). This studies generally agree that the transition from an institutional life to a life in a community brings improvements in quality and positive changes in many other aspects of life (McCarron *et al.*, 2019; Hamelin *et al.*, 2011; Lemay, 2009; Kozma, Mansell and Beadle-Brown, 2009). Generally speaking, life in community settings is linked to a better quality of life and subjective well-being (Sines, Hogard and Ellis, 2012; Kozma, Mansell and Beadle-Brown, 2009; McConkey *et al.*, 2018).

Some studies indicate also that deinstitutionalization was extremely difficult for some people with intellectual disability (Mansell, 2006; Owen, Hubert and Hollins, 2008). Living in a community is not necessarily a positive experience or integration in that community by default. It changes over life course and depends on many aspects such as location of housing unit, transportation, available community activities, attitudes of the society, person's social skills, cumulative disadvantages, etc. (Abbott and McConkey, 2006; Bele and Kvalsund, 2016).

Therefore, it is important how the process of transition from institution to community is planned. As Mali (2019) underlined, planning to move from a long-term institution to community-based setting involves engaging the service user as well as planning specific support tailored to her/his needs. The process of moving from institution to community should be based on a concrete personal plan that expresses the service user's desired lifestyle and is operationalised through goals with different deadlines, necessary activities and resources (Flaker *et al.*, 2013).

During the phase of planning relocation, all key stakeholders from the user's environment should be included, especially the environment the user is entering. Moving from an institution to one's own family or a non-institutional form of care should not be incidental for all persons affected by the event. If the resident or user is moving to a non-institutional form of support, such as a group home, the preparation should provide the opportunity to familiarize other members of the housing community with the arrival and motivate them to accept the new member as much as possible (European Expert Group, 2012).

A transitional phase should be ensured in which the user in the deinstitutionalization process and other residents of the residential community are able to establish contact, get to know each other better and build relationships with each other. Regardless of age, disability or other characteristics, the ongoing nurturing of existing (friendly) relations during the relocation process should be encouraged (European Expert Group, 2012; Head *et al.*, 2018).

The European Expert Group (2012) says that when preparing to move a user from institutional care, staff should receive information about the person and enable them to establish relationships. It can be done by staff visiting the person while still in the institution. Afterward, visits should be allowed in the other direction, i.e., the user meets the staff (and other users) of the future housing unit. At that time, the user can bring some of their belongings so that they already have most of their furniture and personal belongings during the final relocation instead of being deprived of them, as may be the case when entering institutional care. Finally, when moving to a new housing unit, i.e., non-institutional care, the process is made easier if people working there are already known by the user or resident, for example from previous work in an institution (European Expert Group, 2012).

Various studies, focusing specifically on people with intellectual disabilities, show that many of service users had no choice in the decision to deinstitutionalise, i.e. they could not decide if and when they would move from a long-term institution to a community-based setting, nor with whom they would share their new living space (Owen, Hubert and Hollins, 2008; Salmon *et al.*, 2019). On the other hand, for some people, deinstitutionalisation was gradual so that they had some transition time to get to know the staff and environment in a new housing unit (Head *et al.*, 2018). The preparation activities involved workshops on independent living, money management, cooking, cleaning, other household tasks (Salmon *et al.*, 2019).

The acquisition of independent living skills mentioned above is also in line with the guidelines of the Transition from Institutional to Community-Based Care (European Expert Group, 2012). But, Flaker and Rafaelič (2023) criticise such a pedagogical view because it may happen that the move to the community is conditioned by the acquisition of these skills. As Rafaelič and Flaker (2021) warn, the service users who are »more skilled« or, broadly speaking, »more capable« are also usually the first to be selected for the move. The consequence may be a delay in deinstitutionalisation (or a complete drop-out) for those who are classified as »challenging« and »less able«. The same authors point out that experts also strengthen their power because they decide on the further course of the service user's life. Instead of asking how to ensure adequate support for all service users, the question is increasingly being asked which service users are »able« or »deserve« to leave the total institution.

For those who ultimately leave long-term institutions, the experience of the deinstitutionalisation process can be very different. Some research shows that some people with intellectual disabilities experienced the move very positively (Perry *et al.*, 2011; Head *et al.*, 2018; Salmon *et al.*, 2019). This was because the transition brought positive changes in their self-perception, their status in relation to others, particularly in their position of power in relation to staff or enabled them to live closer to family members (Head *et al.*, 2018; Salmon *et al.*, 2019).

On the other hand, several studies have found that the move was a particularly difficult experience for some people with intellectual disabilities, for a number of reasons, including the loss of relationships with staff and other service users (Owen, Hubert and Hollins, 2008; McCarron *et al.*, 2019). The purpose of this research is therefore to find out how people with intellectual disabilities were prepared for the move from long-term institutions to community settings, mainly organised group homes.

4 Research design

The European Expert Group on the Transition from Institutional to Community-Based Care (European Expert Group, 2012) was considered as conceptual frame for the implementation of deinstitutionalisation, i.e. the move from long-term institutions to community-based settings, and was used to select criteria for a better understanding of deinstitutionalisation process in Croatia. The involvement of service users in each segment of the deinstitutionalisation process is the most important factor for the quality of implementation (Salmon *et al.*, 2019). Therefore, knowledge of their perspective is extremely important and can lead to a better understanding and improvement of the process itself (Videmšek, 2013).

My research problem is related to examination of the process of moving people with intellectual disabilities from long-term institutions to community-based settings.

The use of a qualitative methodology was chosen as it makes it possible to emphasise the importance of personal stories, i.e. to place them at the centre of research interest (Zaviršek and Videmšek 2009; Grebenc and Šabić, 2013). It also facilitates the acquisition of knowledge as a common good and the recording of the testimonies of people who would otherwise remain unheard if they are not allowed to talk about their lives (Urek, 2021).

A qualitative approach allows the researcher to focus on what is really the critical point for respondents (Milas, 2009). It also highlights different perspectives that describe certain phenomena (Adu, 2019). Within the qualitative approach, there is a very long tradition of the ethnographic approach, which emphasises that knowledge is best gathered from participants in their natural, everyday environment (Creswell and Creswell, 2018). The skills required for ethnographic work broadly coincide with the skills used in social work and enable a deeper understanding of the processes related to different individuals, groups and communities, particularly those on the social margins (Gillingham and Smith, 2020).

Considering all above, the focus of my research is on the experiences of moving from a long-term institution to a group home, from the perspective of people with intellectual disabilities. For this purpose, the following research questions were posed:

1. What are the reasons for moving from a long-term institution to a group home?
2. What criteria do they (service users) need to meet to be chosen for a move from a long-term institution to a group home?
3. What was the moving from a long-term institution to a group home like?

The research population are people with intellectual disability who live in group home settings in Croatia. In line with the general objectives of qualitative research and the specific aim of this study, greater importance was placed on involving different members of the population whose opinions and experiences are to be known and understood in detail, which is why purposive sampling was used (Campbell *et al.*, 2020). Sampling was carried out in two phases. In the first phase, from the official list of all group home service providers (20) in the Republic of Croatia, 11 group home service providers were purposively selected to obtain both state institutions (5) and non-governmental organisations (6) located in different parts of

Croatia. In the second phase, all sampled group home service providers were asked to complete a questionnaire on socio-demographic and other characteristics[4] for each service user which meets the population criteria of this study.

Based on the data obtained, a purposive sample was made to include participants who could provide different and multi-layered insights into the topic. A total of 14 male and 13 female participants took part in the study. The youngest participant was 19, the oldest 69 years old, the shortest stay in a long-term institution was 1 and the longest 53 years, while the shortest stay in group homes was 1 and the longest 7 years.

I collected the data during a stay of several days in the participants' housing units from April to September 2021. The semi-structured interview method was used in such a way that participants were interviewed individually about their life experiences[5] during the moving to group home. The data analysis was conducted according to the guidelines of Braun and Clarke (2006). This requires a detailed familiarisation with the data, which was achieved by the researcher conducting the interviews independently, transcribing them and reading the transcripts several times. Next comes the formation of initial codes, i.e. ideas, concepts and notes on interesting findings. This is followed by the grouping of codes into potential themes and checking whether there is a logical continuity between the data, codes and themes in both directions. Finally, the final codes and themes need to be refined, which is additionally analysed in the context of the existing literature when writing the research report.

5 Results

5.1 Reasons for moving from a long-term institution to a group home

Respondents explained that the most often the reason they moved from a long-term institution to a group home was necessity, because the long-term institution was closed or they did not have the option of returning to their own family:

> And there, [name of a long-term institition] is no more, it's locked closed, everyone moved out. (Iris[6])

A large proportion of participants did not know any reason why they moved from long-term institution. The decisions about moving to a group home was done by other people, i.e. social workers, other service provider staff or

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[4] Age, sex, number of years in a long-term institution, number of years in group homes, deprivation of legal capacity, multiple disabilities, ability to express oneself verbally, education, level of support provided.

[5] Set of five topics discussed with the participants during the interviews: a person's life course from early age till now, experience with institutionalization, experience with deinstitutionalization, current life in organized housing, and a vision of one's future.

[6] All names used are pseudonyms.

decisions made by family members. Respondents were not asked about their wishes and expectations:

> My sister requested it for me. (Ivy)

In some cases the respondents stated that the reason for moving was their independent request, often motivated by dissatisfaction with life in the previous long-term institution:

> I couldn't live with them anymore … what can I say … I asked to come [to group home]. (Karl)

Other studies present similar results. The closure of an institution is also cited as one of the most important reasons for deinstitutionalisation of people (Hubert and Hollins, 2010; Drake and Herbert, 2015). The deterioration of buildings and blocking investments in institutional care due to the financing requirements of EU funds forced the closure of parts or sometimes an entire long-term institution (Mladenov and Petri, 2020). Instead of criticizing institutionalism, the reasons for closing an long-term institution are found in economic and managerial goals (Miettinen and Teittinen, 2013). Service users are not involved as these decisions are being made by management and higher levels of government (Hubert and Hollins, 2010).

It follows that the reasons for the move do not lie in the affirmative goals of deinstitutionalisation, such as living independently in the community. This even applies to participants who have endeavoured to move on their own initiative. As it is common for people who have difficulty functioning in daily life to be returned to a long-term institution (Broadhurst and Mansell, 2007), this process is the opposite. Indeed, while in an long-term institution, participants were obviously in constant contact with the service users who had caused them difficulties. It did not make sense to move these »problematic« to another long-term institution. Relocating the aforementioned participants to the group homes, as a kind of separation from the »problematic« service users, was the optimal solution, which they saw as the reason for their deinstitutionalisation.

On the other hand, the dominance of experts and family members in decisions about the service user's life is actually based on the cultural assumption that people with intellectual disabilities are not able to make independent decisions (Wiesel *et al.*, 2020). Other studies also show that service users were not significantly involved in shared decision-making about the move (Björnsdóttir, Stefánsdóttir and Stefánsdóttir, 2015; O'Doherty *et al.*, 2016; Mihanović, 2019). This means that the most of participants had no influence on whether they would move from a long-term institution to a group home because it was a process that just »caught« them and they had no choice.

5.2 Criteria that service users need to meet to be chosen for a move from a long-term institution to a group home

One of the most frequently mentioned criteria by participants is functionality, which manifests itself in independence of movement, self-care, good health and developed skills:

> She would also like to get accommodation at the apartment. But not selected because of the wheelchair. (Chris)

On the other hand, fulfilling tasks such as school attendance, regular participation in organised activities and absence of behavioural problems also proves to be an important aspect of criteria called »good behaviour«:

> Must be nice, must be polite, must be honest, no fighting no steeling. (Jan)

However, it is interesting to note that some of the participants know that there are certain criteria, but the assessment of whether they are fulfilled depends solely on the experts. Finally, some of the participants did not know any of the criteria that have to be met in order to be chosen for a move from a long-term institution to a group home. It cannot be attributed to intellectual difficulties either, as several participants answered other questions very meaningfully.

This contrasts with the theory of deinstitutionalisation, where the key criterion should be the individual's desire to be included in the relocation (Flaker and Rafaelič, 2023). The recognised criteria actually reflect the functionalist paradigm and the medical model, which focus on the difficulty and need to »fix« a person so that they fit into societal expectations (Leutar and Buljevac, 2020).

Foreign research shows that deterioration in health can be a crucial factor in the decision to institutionalise someone (Werner, Edwards and Baum, 2009; McKenzie, Ouellette-Kuntz and Martin, 2016). In this sense, improvement or stabilisation of health status may be a criterion by which the need for institutional care is eliminated, opening up the possibility of using less intensive forms of care such as group homes.

Accordingly, Martin and Ashworth (2010) found that service users who were assessed as being more functional in self-care and requiring less medical care were also selected for earlier exit from institutional care. In addition, service users who are involved in a range of activities, most of which are provided by the long-term institution, have also been shown to be the first to exit the institution (Martin and Ashworth, 2010).

The above supports the earlier criterion of »functionality«, but at the same time implies the importance of adequately meeting the demands placed on service users such as school attendance and regular participation in organised activities. The absence of behavioural problems also proves to be an important aspect of the criteria that could be summarised as »good behaviour«. In other studies, behavioural difficulties actually act as a preventive for deinstitutionalisation (Owen, Hubert and Hollins, 2008; Hubert and

Holins, 2010; Spagnuolo, 2016). Moreover, behavioural difficulties can be an important trigger for reinstitutionalisation (Broadhurst and Mansell, 2007).

5.3 Move from a long-term institution to a group home

Participants in the current research participated modestly in the whole process of preparing for deinstitutionalisation. More specifically, for most participants there was no prior clear and sufficiently early informing about how and when the move would take place, but such a possibility actually came as a surprise to them:

> First, I went to [cousin's name] for Christmas and New Year. Then [name of social worker] called a day or two before that she would be here that day. We were shopping when the mobile phone rang. They were coming to pick me up. (Sarah)

Furthermore, it is surprising that most participants stated that their preparations consisted of packing up the clothes. If there were more extensive preparations, they apparently went unrecognised by a large proportion of the participants in the current study, i.e. they did not associate them with their own deinstitutionalisation.

However, four participants stated that they had the opportunity to see the housing unit before the relocation, and only two of them were involved in the work related to the furnishing of a specific housing unit. In other words, for most participants, the first arrival in the housing unit was at the same time a temporary stay in the same, without achieving a transition period.

Similar findings are found in some foreign research, where participants also stated that they suddenly found out about the move, which they did not discuss in detail, what contributed to the sense of chaos and subsequent problems (Owen, Hubert and Hollins, 2008; Drake and Herbert, 2015; Head, 2017).

Furthermore, the findings of the current research confirmed the previous warnings of the Disability Ombudswoman (2015) that service users do not undergo adequate preparation in the deinstitutionalisation process. Such difficulties also appear in research abroad (Owen, Hubert and Hollins, 2008; Hubert and Hollins, 2010), but there are also numerous examples of adequate preparation, which includes working on acquiring daily independent living skills, such as cooking, doing laundry, maintaining one's home, taking care of one's hygiene and health (García Iriarte *et al.*, 2016; Head *et al.*, 2018; Salmon *et al.*, 2019).

A particularly important aspect of preparation is the choice of people to live with, the choice of housing unit and its furnishings (Head *et al.*, 2018). Other research also shows that people with intellectual disabilities have limited choices about where and with whom they live (Stancliffe *et al.*, 2011; Deguara *et al.*, 2012; Salmon *et al.*, 2019; Niven *et al.*, 2020; Mihanović, 2019). This contributes to the further deepening of the power imbalance between staff and users, as service users effectively have to live with those whom staff refer or »judge« to be the most appropriate.

Considering the aforementioned lack of information and preparation, it is not surprising that some of the participants in current research stated that the relocation itself was an unpleasant experience for them. Similar findings have been noted in foreign research, where some people with intellectual disabilities also reported various difficulties in relocating (Owen, Hubert and Hollins, 2008; Drake and Herbert, 2015). Consequently, the negative experience of moving into the community is associated with worse outcomes, i.e., detoriation of the quality of daily life (Kozma, Mansell and Beadle-Brown, 2009).

However, for most participants in my study, move is still a pleasant experience, which is consistent with the findings of numerous authors (Drake and Herbert, 2015; Head, 2017; Angell *et al.*, 2020). Nonetheless, in the cited studies, participants indicated that move was a positive life event because it brought them greater independence, more opportunities to organise their own leisure time, more opportunities and involvement in activities in the community and related opportunities to socialise, generally more activities in everyday life, and much more. The above is consistent with the reasons for deinstitutionalisation, so it can be said that service users have internalised and actually achieved it to some extent.

Finally, in other studies, participants often associated the move from a long-term institution to the community with various losses, particularly social relationships with other service users and staff (Owen, Hubert and Hollins, 2008; Head, 2017). Despite this, the current study did not find that preparation for relocation implied working to maintain social contacts, but participants also did not problematise their loss during the deinstitutionalisation process. This seems to indicate the strong influence of institutional culture that led to the breakdown of social relations and mutual alienation between people who in some cases had spent decades of their lives together.

6 Discussion

The fact that the deinstitutionalisation process started much later in the post-socialist countries than in the Western countries could be a kind of advantage, because a body of theoretical knowledge and empirical research has already been created that can be used to improve the process (Zaviršek, 2017; European Expert Group, 2012). Nevertheless, it seems that the previously well-documented mistakes persist even in new waves of deinstitutionalisation. More precisely, in the Croatian context, good preconditions were created, several smaller deinstitutionalisation projects were piloted, strategic documents were adopted, funds were secured and a positive political climate was created to start the process (Disability Ombudswoman, 2015; 2022). In other words, in Croatia a top-down approach was chosen, in which the impetus for implementing deinstitutionalisation comes from the authorities and management structures.

The problem, however, is that such an approach often does not reach the actual people, i.e. the service users (Rafaelič and Flaker, 2021). They do participate in the deinstitutionalisation process, but not in a way that enables them to better exercise the right to self-determination, freedom of choice, the right to live in a community and other benefits, but often only because it is required of them in order to fulfil certain policy goals.

The features of the medical model and the previously established position of power that characterised the situation of institutionalisation are also identified in the present in research. In this sense, the process of deinstitutionalisation does not bring participants as service users anything new, but a further deepening of the exclusion from decisions about their own lives.

It follows from the above that service users themselves develop neither personal nor political power to demand a further improvement of their own position and thus at the same time the continuation of the deinstitutionalisation process. Instead, the most important and often only driving force remains the withdrawal of financial resources, especially from EU funds (Mladenov and Petri, 2020). When these are exhausted, the process comes to a standstill and the results achieved gradually collapse as the vacancies in total institutions are filled again with new service users (Disability Ombudswoman, 2022). This is supported by the fact that in Croatia only in 2014 and 2015 a larger number of relocations from long-term institutions to community-based services were recorded, while in the following years this number was extremely low, with the number of people in long-term institutions actually increasing (Disability Ombudswoman, 2022; Ministry of Labour, Pension System, Family and Social Policy, 2023).

Criticism of the recent wave of deinstitutionalization in Croatia is important to consider when endeavoring to improve general practices. The new wave of deinstitutionalization planned in the coming years, should not repeat the same mistakes. Some changes have been observed at the policy level. A new, comprehensive National plan for the development of social services for the period 2021–2027 (hereinafter National Plan) has been adopted (Ministry of Labour, Pension System, Family and Social Policy, 2021). Using international and national documents and strategies as the basis, the National Plan declares to take the same direction as decided in the first wave of deinstitutionalization.

There are plans for new forms of social services such as care leave, and peer support which in addition to the legally guaranteed new personal assistance service, should ensure the prevention of institutionalization. The focus is also on ensuring the quality and availability of social services regardless of place of residence in Croatia (Ministry of Labour, Pension System, Family and Social Policy, 2021).

Accordingly, there is criticism that the set goals do not go far enough, given that, for example, the availability of social services should be guaranteed, and not highlighted as a key goal (Opačić, 2022). In addition, although generous funds are planned for the implementation of the National Plan, predominantly from EU funds, the situation is reminiscent of previous scenarios where deinstitutionalization occurs only if financial motivation exists. It seems that even the new wave of deinstitutionalization fails to a radical change among all stakeholders, hence the justified fear of perpetuating the previous mistakes, but even more dangerous is the ongoing deterioration of many people who will remain or end up in a long-term institution.

6 Conclusion

The recognised reasons for moving from long-term institutions to group homes are not in line with the goals of deinstitutionalisation and reflect the marginal role of service users. In this regard, the recognised criteria by which someone is selected for inclusion in the aforementioned process still largely reflect the medical model of care. Another overwhelming fact is that the participants felt that there was no meaningful preparation for transition. In the end, although the move was a difficult life event for some of the participants, it was still perceived as a positive change for most of them.

These findings provide an important insight into the experience of deinstitutionalisation and can help stakeholders at different levels. In particular, it is important for social workers to pay more attention to planning for deinstitutionalisation. In this sense, social workers should provide timely and appropriate information to service users. Particular attention should be paid to ensuring that moving into a community does not become a privilege for a select few but is an option for every person living in a long-term institution.

Existing methods, such as personal planning, should not be disregarded, as was the case with the participants in my study. In this regard, planning for the move should certainly include a transition period where service users have the opportunity to choose where, with whom and how they want to live. However, moving to a group home does not end the process of deinstitutionalisation, but continues in a further process of integration into the community, to which social workers can also make an important contribution.

In addition to all the known guidelines for deinstitutionalisation, it would be useful in the following research to find out what service users think might help them in the process, i.e. their move to the community. This knowledge should then be used to revise the existing guidelines and create new ones, because it comes from the key stakeholders – the service users themselves.

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