

Falling through the cracks: critical review of the deinstitutionalisation process in a post-socialist state.

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Abstract

Throughout Eastern Europe, the attempts to carry out successful deinstitutionalisation (DI) have been hampered by the legacy of Soviet-era practices of care. In Latvia, it is present in the form of residential schools for children with special needs which continue to host a large proportion of children with disabilities. In order to monitor the progress that has been made since ratifying the UN Convention on the Rights of Persons with Disabilities a nationwide evaluation of accessibility of employment and education was carried out. Using the data from this work, we argue that due to the fragmented implementation of DI and lack of a child centred approach throughout the education sector, despite educators firmly believing they are acting in the best interests of children, current practices of care contribute to the creation of 'inclusive exclusion'. Using the theoretical framework of Giorgio Agamben, we propose viewing the current approach to DI as one that sustains the exclusion of children with disabilities by increasingly marginalising children with severe disabilities by keeping them segregated in special forms of residential care. We show how this approach is primarily rooted in the specialist-based approach being seen as the most effective form of care for children with disabilities.

Keywords

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Introduction

Once it was announced that the deinstitutionalisation process had finally reached Latvia, the only question most people had was — how is it going to be subverted? It was clear that there would not be organised opposition to the process, but at the same time it was clear that it would never succeed. This article is dedicated to explore local idiosyncrasies and entrenched institutional perspectives that allow institutions to be preserved, transformed and maintained even as they are officially being shut down. By presenting three stories of how children with disabilities and their families experience the institutional framework and learn to survive in it, we hope to contribute to a better understanding of possible shortcomings of the deinstitutionalisation process where it is implemented in a way that precludes full awareness of all of the actors in their new roles and the kind of changing practices of care it involves.

If viewed from a top-down perspective, support for people with disabilities, efforts to promote deinstitutionalisation, and the inclusion agenda in Latvia is being administered by the Ministries of Welfare, Education and Health. In this model, each ministry is responsible for a fraction of the support at times making it difficult for their employees to coordinate particular policy initiatives. By way of example, there are two vocational schools that offer education for people with disabilities, yet one school is governed by the Ministry of Welfare while the other is under the responsibility of the Ministry of Education.

If viewed from a bottom-up perspective, people with disabilities will often come in contact with non-governmental organisations (NGOs). They work as information providers that also execute particular state funded initiatives and allow for sociality. Although people with disabilities generally appreciate the work of NGOs, it is implied that NGOs have to exist only to cover for the lack of an effective and easily understandable state system of support.

The existing model puts a lot of responsibility on the people working as career consultants, teachers within regular schools, and so on (either with or without special programmes). On the one hand, norms of inclusion have been written into existing laws (a child has a right to study in the nearest school; career

consultants should have expertise on employment for people with disabilities; and so on). On the other hand, no comprehensive road map for allocating finances towards school infrastructure and personnel development exists. A school principal has to either deny a child with disability her rights by sending her away or deny her rights by admitting her and providing less than adequate services. We are not advocating such a perspective of two limited choices or arguing that this is the opinion of everyone involved. Instead, such a lose-lose scenario serves as an introduction to the challenges of the current deinstitutionalisation process in Latvia.

Current context

Giorgio Agamben's philosophy of sovereign power and bare life serves as our main theoretical standpoint for analysing the effects of deinstitutionalisation on children with disabilities. Agamben argues that sovereign power produces a political order based on the exclusion of bare life (Agamben, 1995). This is done by enacting the exception in which normal legal processes are suspended, the human being is stripped of legal status, and transformed into a bare life without rights. In Agamben's view, this means that an individual is forced to be a 'good citizen' or risk losing the state's protection and therefore the rights that come with it.

We offer to expand the analysis of Agamben and similarly of Zigon (2011) and Završek (2009) to explore how the 'state of exception' and 'inclusive exclusion' can be used to better explain the place of other marginalised groups in contemporary society.

Zigon (2011) in his work *HIV is God's Blessing: Rehabilitating Morality in Neoliberal Russia* emphasises the importance of spatially removing the addicted persons from society, therefore effectively forming non-places where they exist in a constant state of exception. Završek (2009), in turn, argues that it is important to recognise that most people who require help from social services are included by exception – the very nature of social services as a system that serves only the neediest stipulates that the individual is in a state of exception which qualifies him/her for these services. This transforms the person from

being an active political individual to a welfare consumer that in most extreme cases leads to exclusion by confining individuals to institutional care.

We combine these perspectives to argue that it is important to recognise institutions for children with disabilities, which exist in Latvia, as places of 'inclusive exclusion' due to a poorly implemented deinstitutionalisation process which leads these institutions not towards dismantling a state of exception, but rather to enforce it, thus ensuring their continued existence. Instead of arguing that an individual in state care exists in permanent state of exception, we would like to show how this state of exception comes to pass due to deinstitutionalisation process which makes their existence impossible both inside and outside of the institution.

Background

The deinstitutionalisation process has been an ongoing effort by countries around the world to decrease the number of people who for various reasons would be institutionalised. As noted by Kuuse and Toros (2017) it can be explained as stemming from several perspectives. Deinstitutionalisation can be seen as a concerted effort to decrease the costs of long-term care, to improve the level of care, or to improve the health outcomes for the former residents of the institutions. Kuuse and Toros (2017) point out that these approaches are promoted by international organisations such as the UN arguing for a human rights perspective on deinstitutionalisation.

In post-socialist countries, the deinstitutionalisation process has been met with considerable resistance from ground level workers in the childcare system and from the general public. As argued by Rasell and Iarskaia-Smirnova (2014) one of the possible reasons is that specialists that were employed in the welfare sector were taught to regard residential care as the best possible solution. At the same time, the high number of children in residential care stemmed from state policies such as deportations, famine, war and repressions. This led to an outlook where children in the institutions were perceived as problematic and connected to either the criminal underworld or their bourgeois/kulak parents (Zezina, 2001). Among other factors, this perception of children in institutions as

morally reprehensible led to a hesitant implementation of deinstitutionalisation in post-socialist countries, including Latvia, where the process earnestly started only in 2015 with the creation of an 'Action Plan for Implementation of Deinstitutionalisation 2015-2020'. Although the laws and regulations for the provision of social services since 2002 have stipulated that institution-based care should be an exception rather than the rule, it took 13 more years to address the fact that for most cases it was the other way around. This was so particularly for children with disabilities in care. Work by Iarskaia-Smirnova and Pavel Romanov (2007) showed that, although the officials and administrators may support deinstitutionalisation and integration for the most part, children with severe disabilities and orphans are still seen as groups that require institutionalisation.

Some research indicates the situation is even worse in Latvia (Legzdina, 2016) where interviews with childcare professionals revealed a lack of faith in deinstitutionalisation. Nevertheless, the situation has been changing in Latvia, as according to official statistics the numbers have been decreasing – in 2010 there were 469 children with disabilities in social care institutions while in 2017 the number has been reduced to 305 (Central Statistical Bureau of Latvia, 2017).

Methodology

Emerging from a broader debate on subjectivity and objectivity in ethnographic writing, fictional ethnography is generally understood as combining ethnographic observations with fictional people, places and events in a single narrative to better explain a particular research setting (Rinehart, 1998; Richardson, 2005; Rottenburg, 2009). We wish to highlight two reasons for using fictional ethnography. First, it enables us to write detailed descriptions of particular actors as persons with multifaceted motivations and concerns without compromising their anonymity and privacy. Second, fictional ethnography allows researchers to expose and explain systemic conditions through storytelling so that the reader can follow how these conditions are experienced by the person and how these encounters shape their further decisions. We will attempt to describe the system of Latvian residential childcare for children with disabilities by telling three stories which, although based on three separate research

participants, incorporate details and insights obtained from multiple conversations with various stakeholders.

The stories are based on research we conducted during the winter of 2016/2017 for the Ministry of Welfare in Latvia. The aim of the research was to evaluate the available support mechanisms for people with disabilities in relation to education and employment. It included desk research as well as discussions and interviews with the relevant stakeholders — principals of schools, state officials, NGOs and people with disabilities. By carrying out interviews with both the relevant authorities and the people who themselves have had experience with these support systems we gained a multi-faceted view on how the support systems are created and experienced in Latvia. The research included 32 semi-structured interviews, 18 structured interviews and 2 focus group discussions that were complemented by secondary research of available information sources. This article draws on this wealth of information and is constructed both from the direct experience of interview participants and from broader trends and repeated stories we learned about. Through using the fictional ethnography approach, we are able to incorporate all of this information in the form of short stories instead of trying to reproduce it in form of numerous tables, arguments and explanations.

By following the trajectories of these children as they went through instances of Latvian education, healthcare and employment, different systemic practices of exclusion reveal themselves, thus allowing for a debate on how the process is experienced by children, and to what extent it was inclusive at the time of conducting this research.

Alice

Alice and her parents did not worry about institutionalised care until the fourth grade (age 10). Sometimes her anger outbursts in school about certain situations created tension, and certain classes had tasks she was not able to perform. While her parents were notified about these difficulties and suggested consulting a psychologist, they were afraid that this could result in them being asked to move her to another school. In fifth grade, the pressure increased as

teachers started to pay more attention to students' performance. Alice was referred to the nearest Pedagogical Medical Commission (PMC) by the school's psychologist. The PMC serves to assess whether a person has special learning needs and to recommend an individual learning plan and one of nine special educational programmes. These programmes are taught and accredited only at certain schools and in most cases the PMC recommends the child changing the school to one with the special programme available. Furthermore, there is often pressure from other parents who see the child as potentially harming others' chances to learn.

The local specialists from the PMC determined that Alice needed a classroom assistant and had to be assessed by a psychiatrist for autism spectrum disorder (ASD). They recommended a special school that was located slightly out of town where Alice would need to be taken daily by car and stay after school until she could be picked up. After a few months of negotiation with a reluctant principal of the school who assured the PMC that the school could not support Alice in the way the other school would, they decided to conform.

In the new school, Alice had access to a classroom assistant, an individual plan, as well as rehabilitation, but the quality of learning was poorer as this was a programme for children with mental development disorders. Compared to her previous experience, the objectives in her individual plan seemed to be behind what she felt capable of doing.

Alice and her parents started to search for ways for her to get better education and develop the necessary social skills, as they were afraid that learning at a special school might affect her progress in the educational system. They contacted an NGO for children with ASD. If before they had seen special needs and disability as stigmatising and being a limitation, then consulting the NGO made them recognise how each of the statuses can grant certain benefits. They managed to get her recognised disability status because it fulfils a requirement outside of special schools in order to get an assistant granted by the school.

Children with ASD get different recommendations from PMCs meaning that you can be in various special programmes with the same diagnosis. Despite the school being very welcoming and providing assistance, visual aids and social

training, after a year Alice's parents pushed for another evaluation at the state PMC which can make changes to the decisions of municipal PMCs.

This time with the help of her psychiatrist's description, it was recommended that Alice should be referred to a programme for children with learning difficulties available at a school closer to her home. The school, however, was not that well suited to a child with ASD, as only a few teachers were aware of certain intricacies of working with her. At least this time she had an assistant as a result of having disabled status. A few years later, after work with the NGO and other parents to support the staff who had previously little experience of children with ASD, the teachers and classes slowly adapted to her needs.

As can be seen, none of the three schools were perfect for Alice as each addressed a different issue and each excluded certain ways of learning, care and socialisation in their own way. Alice was pushed out of the first school, but the second time her parents decided to move her out themselves because of the stigma resulting from long-term institutionalisation and segregation of children with disability. Special education is seen by many parents as the best option as there are better possibilities to get an individual approach to learning, there are fewer children in class and there is more community involvement. At the same time, being at a special school does not solve the problem of being excluded and misunderstood in other contexts, which is particularly visible and important for people diagnosed with ASD, where social interaction is one of the major criteria.

Eventually Alice's parents changed their strategy from avoidance to working closely with the school staff, going through possible adjustments with the newfound knowledge gained from the help of the NGO. In many cases, parents do not communicate their child's potential special needs to the school; but without communication inclusion becomes complicated. While the aim of this strategy is to avoid institutionalisation, it comes with a high risk to facilitate it.

In this sense, Alice and her parents were contesting the claims of both special and general education to be inclusive. If the issues of inclusion are not taken as a right, but instead are mediated through approaches that medicalise the issue at hand, as in the PMC evaluations and applying for disability status, the possibility to make a change is decreased. As has been argued, inclusion

demands that the politics of exclusion and representation are addressed (Slee, 2007; Hassanein, 2015), but in none of Alice's school experiences was the medical model of disability fully overcome by social considerations. Alice got an assistant because of her disability status and the place at a mainstream school through the recommendation for a special programme that the school had accredited. Therefore, in order for Alice to claim her right to be at a school, her issue had to be medicalised. Disability became an object of interest both when she was seen as not belonging where she was and when she wanted to belong somewhere else.

The few schools in Latvia that have moved towards a more inclusive organisation of their work have done so based on particular cases where a child provided cause to evaluate their practices. In most cases, the pressure comes from parents of relatively high socio-economic status who have been able to demand support at municipal level. The basis of such possibilities comes from Section 17 of the Education Law (Latvia, Saeima 1999), which makes the municipality responsible for granting every child the right to learn at a school that is closest to their home. In this sense, deinstitutionalisation starts with the law that can be used by parents to ask for change to the school closest to their place of residence. The scenario in such cases is usually that the parents convince the school management of the need for adjustments in infrastructure or staff training and the schools work this out with the municipality to get appropriate funding. In Alice's case, it granted the school to make adjustments based on her needs. At the same time, she was still part of a special programme where she was together with other children excluded from general education.

It is common for teachers and managers of schools to think that due to a shortage of resources and lack of training their schools cannot be inclusive for children with disabilities. They try to exclude these children from mainstream schools and move to special schools, an approach which creates an environment of mistrust and limits possibilities for inclusion that requires a lot of co-operation and exchange of information between doctors, parents, teachers and children. Schools that aim to be inclusive strive to organise more training for teachers and parents, hire assistants and provide assistive technologies. The same goes for

schools which have accredited special programmes, as the teachers are required to go through training and resources are allocated to work on inclusion.

If deinstitutionalisation requires schools to introduce specific institutionally managed ways of care, the schools that are first in line to adjust slowly develop expertise as 'special' schools as they attract more children with disabilities and special needs. Including children with disability and special needs makes these schools an exception since their inclusion into special programmes attracts more resources to the school. Reforming the educational system to enable new teachers to give significant attention to inclusive education will take years to bear results in the classrooms. As deinstitutionalisation aims to close or transform boarding schools and decrease special schools, many such schools in Latvia are now working to become 'inclusive' schools, a change that is regarded as being essential. Special schools are reorganising to become resource centres for general schools, but their challenge is that the practices at special schools are different from how social life is organised in inclusive schools. For the time being, children like Alice exist somewhere in between.

Kristers

Kristers' hometown is located near a small river that during springtime gathers just enough water to allow for canoeing. When Kristers was 11, he went for a family trip during which his left eye was accidentally hit by a paddle. He underwent surgery which seemed successful, yet shortly after complications began. The surgery had caused an infection that now had spread to both of his eyes and caused irreparable damage. Kristers became unable to move around the town on his own, make sense of letters on the blackboard and read regular schoolbooks.

His school had no previous experience with students with visual impairments. For a few weeks while Kristers' parents held talks with his teachers and school principal, Kristers continued in the same class. His sister helped him walk to and from school, and his best friend helped him around. Although his education continued, the school staff made it clear that this was only a temporary solution and Kristers would eventually have to leave.

Historically the support for people with visual impairments in Latvia has been concentrated on the outskirts of the capital, Riga, at what was commonly referred to as 'the village of the sightless'. Nowadays it contains a library, a boarding school from pre-school to secondary school level, a rehabilitation centre and an association devoted to vision related disabilities that also co-ordinates some social entrepreneurship incentives. The district is equipped with sidewalk rails, the local shopkeeper is aware of people's needs and the traffic lights have a signalling beep.

The only school suggested to Kristers was located within this district. The school had infrastructure adaptations, learning materials, trained staff and a special learning programme for learners with visual impairments. Kristers was still overwhelmed with trying to re-learn doing everyday things when he learned that due to his hometown being 110 kilometres away, he would have to reside in this institution during weekdays.

For a few years, Kristers learned the necessary skills to become as self-sufficient as possible, continued his education at the boarding school and learned Braille. There were periods when Kristers felt depressed and did not travel home during the weekends. Noticing these changes in Kristers, his parents decided he should leave care.

Since the accident, his parents had followed developments in the state, municipality and NGO support networks. During the last year of primary school, they actively consulted with NGO specialists and Kristers' boarding school to learn pedagogical methodologies that could be used for Kristers and provided the teachers from Kristers' hometown with examples of what he was capable of doing. For example, by consulting with the Latvian Academy of Sport Education Kristers' parents were able to forward some information to the local sports coach. The previously reluctant principal was convinced when he learned that Kristers was the first student of his boarding school to attempt and pass the state examination (non-obligatory). Ultimately, Kristers' parents found an apartment that was closer to school so that once Kristers got acquainted with the surroundings he was able to navigate the way to school on his own.

An analysis of Kristers' story shows that his educators did not believe institutionalisation was desirable, they believed it was necessary. The effects of this perspective can be seen throughout Kristers' story. For practical purposes, the state deemed specialist care sufficient, while the physical and social environment available to Kristers was limited. Boarding school students were expected to continue their education at the same place, and there was no precedent for students willing to face countless difficulties in striving for regular education. What Kristers' story shows vividly is that systemic circumstances made it reasonable for children with disabilities to accept being and remaining excluded. This begs the question: what reasoning makes it possible for a specialist care paradigm to co-exist with efforts to encourage inclusion?

Firstly, Kristers' boarding school was on the very outskirts of Riga. The physical environment was designed according to Kristers' needs but only so far as the district boundary went, which produced effects of exclusion. This has been recognised by authors unconcerned with the way exclusion through inclusion is theorised by Agamben (see Biehl, 2005 and Comaroff, 2007) and also authors attempting to develop his perspective (see Zigon, 2011 and Završek, 2009). For example, Zigon was fascinated with how a site aimed at turning those with HIV into 'appropriate' citizens was located only 20km away from St Petersburg. Similarly, since this community is located on the outskirts of the city, children with disabilities were reminded of their qualitative difference from the 'real' citizens. Thus, spatial exclusion not only confines but also demarcates the possibilities and difference, easing the way into trajectories of marginalisation.

Secondly, effects of exclusion continue as children age and pursue careers. Our research found that career advisers in mainstream schools generally lacked the competencies required to consult children with disabilities. Also, being spatially confined, children learned of careers that are popular among other residents. For one of Kristers' acquaintances choosing to be a wicker weaver resulted in primarily interacting with the people from the district. For another, studying to be a masseuse in an EU-funded project resulted in studying and working together with some of his schoolmates. As the overall employment system is not inclusive, it is also reasonable for NGOs to seek out particular types of jobs that would require less preparation and extra effort from both people with disabilities

and employers. Being in the boarding school would likely affect the career opportunities Kristers would be encouraged to consider.

Thirdly, the state incentives for inclusion contributed to this cycle of exclusion. NGOs temporarily hired their clients in state funded subsidised employment incentives, thus both providing their clients with job experience and confining them to the social circles of disabilities. Many of the people interviewed for this research voiced their critique of Section 109, Part 2 of the Labour Law (Latvia, Saeima 2002) which prohibits employers from discriminating against people with disabilities. The provisions of this section put employers at risk of being sued, which can prevent employment in the first place.

The arbitrary gain of state support for people with disabilities may best be understood with reference to funded assistant services. Assistants do not receive any prior training and the job is under-paid. In the case of municipality-funded assistants, regular accounting sheets must be completed in order for clients to continue receiving the service. The low pay often results in relatives serving as assistants, while excessive paperwork in some cases results in families refusing the service and paying an assistant from personal funds. All three of these examples serve as a bleak illustration of how ineffective inclusion incentives may further aggravate exclusion by reminding a person he or she is not able to function socially at times when assistance is unavailable.

Fourthly, exclusion through inclusion works by marginalising people with disabilities through welfare (Zaviršek, 2009). Our research participants told us that people with disabilities are often offered jobs that require low qualifications and offer little pay. If the support they could receive through welfare is similar to their potential salaries, they may choose not to work. The short-term effect of this is exclusion of people with disabilities from employment. In the long-term this normalises welfare as income, again reminding people with disabilities of their qualitative difference from others.

Zaviršek argues that political rights and equality (or citizenship, in Agamben's terms) may only arise from efforts of inclusion that are demanded by the excluded group itself (Zaviršek, 2009). At the time of our research, a few NGOs, but mostly parents of particular children, served as agents of change by

consulting state and municipality representatives of children's needs and demanding fair treatment. The parents interviewed saw themselves as the true deinstitutionalisation movement, not only recognising the flaws in state deinstitutionalisation policy but, more importantly, their own political capacity and determination to demand inclusion. It is important to note that we do not argue that residential care in itself caused exclusion for Kristers. His example clearly shows that it is rather the specialist care paradigm which produces the state of exclusion instead of institutionalisation itself. By leaving the decision of what constitutes the disability and what are the appropriate tools for inclusion in the hands of experts the Latvian system fails to adequately implement deinstitutionalisation and rather contributes to the complexity of everyday life of people with disabilities.

Linda

Linda has lived in institutions almost all her life. As she reached the age of three, it became evident that she had cerebral palsy. As her parents did not feel they would be able to take care of her they decided to give her away to a state institution. Adoption rates in Latvia are low and at the time of her birth (Linda was born during the late 90s), they were even lower. Her situation was exacerbated by her disability which destined her to end up in one of the state's children homes. As she reached school age, there were only a handful of options available to her – with disability as severe as hers there were few choices and all of them were a form of state care institution. The children's home decided that she should study in one of the state's boarding schools. This practice was seen as logical and very financially beneficial for the children's home as it still received funding for caring for the child while the actual care was carried out by the boarding school. This is possible because boarding schools in Latvia are mainly recognised as educational institutions and not as a form of out-of-family-care.

Linda, despite her physical constraints, was a gifted child and was able to finish her assignments and follow the learning material without much difficulty. This helped her to finish compulsory education with relative ease. In the Latvian system, children attend compulsory nine-year basic education and then move on

to three-year secondary education. Secondary education is not compulsory, so there was little incentive for the children's home to look for a place that would accept Linda. Her boarding school received money according to the number of students they were willing to board which led to Linda staying at the boarding school for the next three years and studying at the final grade of primary education.

After reaching the age of 18, Linda was forced to leave the boarding school as by this age students are legally required to leave basic education institutions. As she was one of the few students determined to continue her education, her only option was a specialised state institution for people with disabilities. This institution provided basic vocational training and had links with a college level institution for people with disabilities which she hoped would allow her to continue her studies. The institution provided different kinds of courses and programmes but due to her disability her options were limited. She was not able to take part in secondary education aside from separate vocational courses because her previous education was in a parallel special education system not integrated into the overall state education system. This meant that, although she had been going to school for 12 years, in the end she still did not receive a diploma that would grant her the right to enter secondary education, the lack of which prevents her from ever entering higher education.

Linda presents a complex case for education and social care systems in Latvia. Zaviršek (2009), basing her approach on Agamben's theoretical framework, argues that one of the ways a person with a disability gets excluded from being an active citizen is by effectively being a welfare consumer which allows a certain amount of basic rights to be denied to the person. In Linda's case, although she received specialised education as a form of state support, in order to receive it she had to give up a right enshrined in Latvian legislation (Latvia, Saeima, 1999), that it is a child's right to receive education as close to her home as possible. This right was taken away from Linda first when she was sent to a boarding school and second when to continue her education she was required to move again to another part of Latvia where there was another specialised institution that was willing to take her.

The case of Linda also shows the problematic space occupied by institutions that cohabit this space of exclusion together with the children. Due to the nature of her disability, Linda was unable to take part in most of the vocational courses that were provided for her by her educational facility which mainly consisted of teaching basic manual skills. At the same time, she was both capable and motivated to learn computer science as her physical impairments did not prevent her from being able to learn how to use and work with computers. However, she was prevented from doing so due to the fragmentation of the system that is even made worse by the irregular place of this institution within the Latvian education system. Linda received her education in an institution that is a part of a larger state agency. Its functions include both administrative (to keep and update registers of people who need support) and practical (offer training programmes, provide professional/social rehabilitation) arrangements to improve the life of people in need of social support. This includes the previously described school and college for people with disabilities. The institution is financed and overseen by the Ministry of Welfare which in itself already constitutes a very particular case in the Latvian system, as most educational institutions are regulated and financed by the Ministry of Education. This creates endless complications, both for the staff of the school and the overall system, regarding certifying the level of education, circulation of information and, as Linda's case shows, also in relation to making the transition from one system to the other.

The state of exception here also harms the desire to use these educational institutions as a tool for progressing deinstitutionalisation – both of them are promoted as integrated learning institutions that welcome students with and without disabilities. But since the vocational school is part of the Ministry of Welfare, only students with disabilities can receive state funding and, therefore, study for free while everyone else must pay up to EUR 1,800 a year effectively barring any prospective students without disabilities. The current complicated space that this institution inhabits in the Latvian care system also means that most of its students are adults who are taking vocational courses as the complex education system prevents more students from joining this place and gaining skills that may result in their reintegration to society.

The experience of Linda also illustrates the urgent need for deinstitutionalisation while shedding some light on the current complications in the way it is carried out. The decision by the orphanage to send Linda away to the boarding school shows they do recognise their own lack of skills and resources to be able to care adequately for children with disabilities. In all three of the cases of Linda, Kristers and Alice the specialised institutions are recognised as places where there is available both the expertise and the equipment to ensure the best possible care for the child. Nevertheless, their flaws not only impact the quality of life and integration of children, but through continued removal of persons with disabilities from the public space it further strengthens the view that this is the only possible solution. Furthermore, the resistance of municipalities can also be seen as stemming from the financial perspective according to Kuuse and Toros (2017), where the main motivation for implementation of deinstitutionalisation is to reduce costs. This is seen as true at state level, as it is claimed to be less costly in the long term. It is possible to fund the transition using EU grants, while at the local level it is mostly seen as both economically and structurally complicated, due to the need to invest more funds into education and loss of funds from the state for the maintenance of special schools.

Concluding arguments

The stories of Alice, Kristers and Linda reveal the often-chaotic trajectories of children with disabilities in changing practices of care. As the ground is shifting from a medicalised understanding of disability to a social one, and from segregated education to rights-based approaches to deinstitutionalisation, children with disabilities are left to find their own directions in a perpetual state of exception. From the one side, there is a need for addressing the politics of representation that construct children with disabilities as destined for certain forms of institutionalised care. From the other, there are practices of families that actively construct their 'neediness' to facilitate DI.

We have highlighted stories where it is easy to identify the agency of children and families trying to make a change and communities willing to provide support. However, the stories are also of 'good citizens' that do relatively well in school and have resourceful parents of higher than average socio-economic

status. Somewhat paradoxically, to show your neediness for DI, you have to be an agent that is particularly eager not to be a *welfare consumer*. Conversely, for persons without such resources, demanding their right to be included is harder to reach and their rights are subject to chance. Changing practices of care and certain initiatives of DI, therefore, can be seen as producing two classes of children and both can be put in situations where they are in high risk of becoming a part of new and potentially worse ways of institutionalised forms of care.

While we can see that top-down and bottom-up approaches have a large impact on changing practices of care, what is often missing is the middle ground: the coordination at municipal and public discourse levels. By this coordination we don't mean only developing more effective resource management and effectively available ways of helping educational and social institutions to become more inclusive and open, but to engage the broader social issues directly. First, coordinating municipal and public discourse has to take the politics of representation seriously as social marginalization is also one of the factors that decreases the efforts to improve diagnostic practices. Second, it has to introduce community-based learning as a part of DI as it is not enough to train only the 'specialists', like social workers or teachers, but principals, fellow children, and parents must be included. And finally, it has to expand the understanding of care beyond residential and institutionalised mechanisms while at the same time removing the stigma. By addressing these issues, we can hope for the most marginalised child to also be recognised as the subject of deinstitutionalisation.

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