

From stigma in the middle of nowhere to stigma in my back yard: changing geographies of stigma following deinstitutionalisation of care in Lithuania

Del estigma en medio de la nada al estigma en mi propio vecindario: geografías cambiantes del estigma tras la desinstitucionalización de los cuidados en Lituania

Egle Sumskiene*

* Institute of Sociology and Social Work, Faculty of Philosophy, Vilnius University, Lithuania

Abstract:

In 2014 the Lithuanian Ministry of Social Security and Labour issued the Action Plan for the Transition from Institutional to Community-Based Care. This plan stipulated creating opportunities for persons with disabilities to receive community-based services. The reform faced significant protests in local communities, who were against their new neighbours with disabilities. In this paper I argue that insufficient address of stigma resulted in deinstitutionalisation of stigma – a process that is taking place parallel to the deinstitutionalisation of care.

The case study utilized observing public meetings, analyzing media coverage on community protests, conducting interviews with individuals having intellectual and psychosocial disabilities, community members, social workers, activists, and experts in deinstitutionalization, along with creating ecological maps.

Research has shed new light on combating stigma through protest, education, and contact (Corrigan & Penn, 1999). The Ministry and the media, identified as main actors in educational efforts, displayed deficient communication strategies; the Ministry's delayed, abstract, and non-localized approach contrasted with the media's role in highlighting potential conflicts, consequently impeding stigma reduction.

Protests in the communities was used to express negative attitudes toward mental illness. The protests were not geared towards combating stigma but, instead, served to amplify it by targeting residents of the group homes.

Encountering well-integrated individuals with psychosocial disabilities reduces stigma, but the research highlights a substantial lack of such encounters; public stigma limits community members' interactions with individuals with disabilities, while self-stigma prompts

people with disabilities to avoid engagement, resulting in limited participation opportunities and infrequent interactions between both sides.

Keywords: *mental health, stigma, disability, community*

Resumen:

En 2014, el Ministerio de Seguridad Social y Trabajo de Lituania emitió el Plan de Acción para la Transición de los Cuidados Institucionales a los Cuidados Basados en la Comunidad. Este plan estipulaba la creación de oportunidades para que las personas con discapacidad pudieran recibir servicios comunitarios. Sin embargo, la reforma enfrentó significativas protestas por parte de las comunidades locales, que se oponían a tener como nuevos vecinos a personas con discapacidad. En este artículo sostengo que la insuficiente atención al estigma dio lugar a un proceso de desinstitucionalización del estigma, que se desarrolla en paralelo a la desinstitucionalización de los cuidados.

El estudio de caso empleó la observación de reuniones públicas, el análisis de la cobertura mediática sobre las protestas comunitarias, y la realización de entrevistas a personas con discapacidad intelectual y psicosocial, miembros de la comunidad, trabajadores sociales, activistas y expertos en desinstitucionalización, además de la elaboración de mapas ecológicos.

La investigación ha arrojado nueva luz sobre la lucha contra el estigma a través de la protesta, la educación y el contacto (Corrigan & Penn, 1999). Tanto el Ministerio como los medios de comunicación, identificados como actores clave en los esfuerzos educativos, mostraron estrategias comunicativas deficientes; el enfoque ministerial, tardío, abstracto y no localizado, contrastó con el papel de los medios, que resaltaron los posibles conflictos, dificultando así la reducción del estigma.

Las protestas en las comunidades se utilizaron para expresar actitudes negativas hacia la enfermedad mental. Dichas protestas no estaban orientadas a combatir el estigma, sino que contribuyeron a amplificarlo, dirigiendo su rechazo hacia los residentes de las viviendas grupales.

El encuentro con personas con discapacidad psicosocial bien integradas reduce el estigma, pero la investigación pone de manifiesto la ausencia significativa de tales encuentros; el estigma público limita las interacciones de los miembros de la comunidad con las personas con discapacidad, mientras que el autoestigma lleva a estas personas a evitar el contacto, resultando en oportunidades limitadas de participación y en interacciones poco frecuentes entre ambas partes.

Palabras clave: salud mental, estigma, discapacidad, comunidad

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Introduction

Macikai social care home for people with psychosocial and intellectual disabilities was established in premises where in 1939-1955 operated Nazi and Soviet concentration camp. For decades Macikai social care home was the largest care institution in Lithuanian, in 1985 it has reached capacity of 610 beds (Germanavicius et al. 2005). This social care home is probably the most prominent example of 28 large care institutions that operated across Lithuania and were the main providers of care for people with psychosocial and intellectual disabilities. Large residential care institutions were often built in distant, remote locations, far from larger settlements and busy roads, and were frequently surrounded by high fences, reflecting historical practices of separating individuals with disabilities from urban centres and mainstream community life (Pūras et al. 2013). These institutions were designed to separate the „labelled persons“ (Link and Phelan 2001) from the rest of society. This segregation persisted for decades and was so deeply entrenched that, in Lithuania—as in other states that emerged from the Soviet totalitarian regime — there were no social policy alternatives for the care of persons with psychosocial and intellectual disabilities. There was also a lack of political will for systemic change. Consequently, society had very limited knowledge about these groups but held deeply stigmatizing attitudes toward them (Shek et al. 2016).

Efforts to deinstitutionalize care have encountered resistance, particularly from local communities opposed to the integration of individuals with disabilities into their neighbourhoods. This resistance, often referred to as the NIMBY (Not In My Backyard) phenomenon, reflects broader societal stigma and fear of change. Scholars such as Piat (2000), Bostock et al. (2000), Terashima (2021), Sibley and Dej (2022), Webb and Dej (2023) and many more have highlighted how stigma fuels NIMBY opposition, posing significant challenges to the process of deinstitutionalisation and threatening its success.

In the context of deinstitutionalisation, local communities find themselves burdened with substantial expectations. While individuals with disabilities and their advocates hope for welcoming and inclusive environments, the government expects these communities to seamlessly accommodate the transition. However, the fears and concerns of community members are often left unaddressed. Many worry that the arrival of “newcomers” could disrupt the social fabric or habitus of their neighbourhoods, potentially altering the community’s character or leading to a perceived decline in quality of life. These anxieties are exacerbated by feelings of exclusion from the decision-making process, as community members frequently report that they were neither informed nor consulted about the relocation of individuals with disabilities into their neighbourhoods (Diržienė et al. 2023). Despite this, large expectations are placed on these communities to facilitate integration without sufficient support, further straining their capacity to adapt and respond constructively.

In this paper, I argue that the failure to adequately address stigma during deinstitutionalisation has led to the emergence of a parallel phenomenon: the deinstitutionalisation of stigma. While the physical infrastructure of institutional care is being dismantled, the social

and cultural stigma associated with disabilities remains largely intact, manifesting in new and harmful ways. The goal of this paper is to critically analyze how stigma shapes the process of deinstitutionalisation in Lithuania and to explore the implications of deinstitutionalized stigma.

The Lithuanian context

Before the official start of deinstitutionalisation in 2014, in Lithuania functioned 28 institutions with approximately 215 residents, ranging from 100 to 550. In total, care institutions in Lithuania employed 3,000 staff members and accommodated as many as 6,000 residents (The Lithuanian Minister of Social Security and Labour 2014).

In the 1990s, Lithuania regained its independence, declared its commitment to democracy and human rights values. Disability activists started visiting closed care institutions, documenting a range of human rights violations, including inhumane living conditions, the denial of personal autonomy and the right to family life, education, and participation in community activities, as well as instances of physical, psychological, and sexual abuse. Reports highlighted the use of physical restraints, forced medical treatments, and inadequate health-care, further infringing on the dignity and basic freedoms of residents (see, for instance, Germanavicius et al. 2006). Advocates argued that these practices violated international human rights standards, such as those articulated in the United Nations Convention on the Rights of Persons with Disabilities, and called for replacing institutional care with community-based services to promote social inclusion and respect for individual rights.

It took almost a quarter of a century after the declaration of independence, when in 2014 the Lithuanian Minister of Social Security and Labour approved the Action Plan (2014–2020) for the Transition from Institutional to Community-Based Care. This plan stipulated creating opportunities for persons with disabilities to receive community-based services and thus live as ordinary life as possible. According to the outlined strategy, the envisioned scenario for the year 2030 involves the complete integration of individuals with psychosocial and intellectual disabilities into community living, accompanied by the closure of all large-scale institutional facilities. The preparation phase (2014–2020) included situation analysis, collaboration with local authorities and non-governmental organisations, assessment of the needs and capacities, drafting municipal plans for the reform. In the second phase (2021–2030), the Ministry of Social Security and Labour (hereafter – the Ministry) focuses on developing the physical infrastructure and human resources, piloting, developing, and delivering community-based accommodation and service provision in local municipalities. Notably, the plan does not address the issue of localized stigma, and the article will further discuss the consequences of this omission.

Currently, approximately 100 newly established group homes operate across Lithuania, each housing about ten residents. These homes are integrated into specific communities and neighbourhoods, designed to foster as much autonomy and independence as possible

for their residents. During the initial stages, the Ministry provided significant centralized support, including regulations, training, legal frameworks, and funding. Over time, however, the Ministry stepped back, leaving primary responsibility to local authorities, which vary greatly in their commitment and capacity to sustain the reform. Additional responsibility now falls on social workers, residents of the group homes, and local communities.

This shift in responsibility highlights the phenomenon of localized stigma, which has become increasingly evident in the implementation of deinstitutionalisation. The ways in which localized stigma has emerged and differentiated itself from other forms of stigma will be discussed in the following sections, supported by an analysis of research data.

Stigma surrounding residential care

In addition to being notorious for their inhumane living conditions, large residential care institutions also served as hubs of intense stigma. The remnants of this stigma are still evident today, even as the reform progresses. Not only are these manifestations still visible, but they also represent significant obstacles to the success of deinstitutionalisation. The following sections will examine the various forms of stigma and their implications for the transformation of the care system.

First, care institutions were surrounded by public stigma, which occurs when large segments of the society agree with the negative stereotypes and prejudices that lead to discrimination (Corrigan and Shapiro 2010). Furthermore, public stigma effectively conferred an unspoken societal endorsement for the segregation and isolation of individuals with psychosocial and intellectual disabilities, categorizing them as deviant and unproductive members of society (Pūras et al. 2013). This often persisted for an indeterminate duration, in many cases extending throughout their lifetimes. Such practices not only curtailed personal freedoms and self-determination of individuals with psychosocial and intellectual disabilities, with the most extreme manifestation being legal incapacitation, but also subjected them to neglect, violence, and egregious violations of their human rights. Consequently, decades of isolating people with disabilities in large, remote institutions led to widespread ignorance and indifference toward them in society. This void was swiftly filled with myths, superstitions, and stigmatizing attitudes, which, as we will later discuss, fuelled resistance to deinstitutionalisation and the relocation of former residents into communities.

Stigma by association, a widespread phenomenon in care institutions, refers to the prejudice and discrimination experienced not only by individuals with disabilities but also by those closely connected to them, such as caregivers, professionals, and even neighbouring communities. This concept underpins the decision to analyse intellectual and psychosocial disabilities as a single case in this paper. In the Soviet Union, children with complex, severe disabilities, autism, or intellectual disabilities were often labelled “uneducable” (Sutton 1988; Iarskaia-Smirnova 1999; Mental Disability Rights International 1999). As a result, they were excluded from the special education system and placed in institutions

that accommodated individuals with various types of disabilities. These institutions became centres of stigma, perpetuating negative perceptions of disability and extending that stigma to those associated with the institutions, including the professionals working there and the surrounding communities. This stigma by association also explains the resistance of many communities to the relocation of former residents of care institutions. Neighbours often oppose such moves, not only due to misconceptions about people with disabilities but also because they fear their neighbourhoods may become associated with disability, leading to potential social or economic consequences. Such opposition underscores how deeply entrenched stigma by association is and highlights the challenges of deinstitutionalisation efforts.

Finally, penetrating and intense manifestations of stigma by association and public stigma resulted in self-stigma experienced by residents of care institutions. Authors of the Modified Labeling Theory claim that public stigmatization often has a harmful impact on a person's internal sense of self (Link et al. 1989). Self-stigma experienced by the residents of care institutions is result of the public stigma, accompanied by devaluation, lack of self-trust and competence as well as absence of independent living skills. Specific terminology used by residents of social care institutions, e.g., calling each other "dependants" (Germanavicius et al. 2005: 13), reliance on staff to take care of every aspect of their lives, unwillingness to leave institution and start living in the community are just a few examples of manifestations of self-stigma. Manifestations of self-stigma of former residents of large residential care institutions are well reflected in a paper by Sumskiene et al. (2023). Those include the internalization of institutionalized behaviours, such as moving in groups and relying on pre-planned activities, limited engagement in self-directed leisure activities that suggests an internalized belief among people with disabilities that they are incapable or unwelcome in more autonomous, community-driven spaces. The preference for structured, predictable environments over spontaneous or chaotic social spaces reveals a protective strategy rooted in fear of stigma, further demonstrating the effects of self-stigma (Sumskiene et al. 2023).

Corrigan and Penn (1999) have divided approaches for public mental health stigma change into three paradigms: protest, education, and contact. Protest is a reactive strategy, which diminishes negative attitudes but fails to promote more positive evidence-based attitudes. Education through information enables society to make more informed decisions but is incomplete without actual interaction between persons with and without psychosocial disabilities. Stigma is diminished when society members meet well-integrated persons with psychosocial disabilities (Corrigan and Penn 1999).

In this paper, these paradigms will serve as a lens to analyze the manifestations of stigma during the process of deinstitutionalisation in Lithuania. By examining the experiences of former residents, community members, and care professionals, the analysis will explore how these approaches have succeeded — or fallen short — in addressing stigma. This stigma-focused perspective will guide the evaluation of the reform's outcomes, as discussed in the upcoming sections, through a critical review of empirical data.

Methodology

To achieve the study's objectives, a qualitative research method was employed — semi-structured interviews with five community leaders and five regional experts of deinstitutionalization. Community leaders are individuals who hold formal or informal positions of influence within a community. They guide decision-making, organising activities, and acting as intermediaries between the community and external stakeholders, such as policy-makers or reform experts. In the context of deinstitutionalisation, they play a critical role in shaping community attitudes, facilitating dialogue, and supporting or resisting changes like the establishment of group homes. Deinstitutionalisation experts are professionals who guide the transition from institutional to community-based care by developing policies, fostering capacity building, and engaging stakeholders to ensure the reform's success.

This method was chosen to understand and deconstruct the phenomenon of community resistance to the neighbourhood inclusion of people with disabilities. Semi-structured interview questions are prepared in advance but allow for flexibility depending on the flow of the interview. Two separate questionnaires were prepared for the study. The first questionnaire, designed for community leaders, consisted of eight open-ended questions. The research questions aimed to explore three main areas: (1) community members' familiarity and experiences with individuals with intellectual or psychosocial disabilities, including the stigma and fears associated with such interactions; (2) the community's knowledge of care system reform and their perceptions and reactions to the establishment of group homes, including the processes and resistance encountered; and (3) the outcomes of the resistance, focusing on what factors contributed to its resolution and how the community dynamics changed as a result.

The second set of questions, intended for regional deinstitutionalisation experts, included nine questions which aimed to explore the following three key areas: (1) the experiences and roles of regional experts in working with individuals with disabilities and implementing care system reforms, including their professional functions and challenges faced; (2) the process of establishing group homes in the communities, addressing community reactions, stigma, resistance, and the impact on the experts' work; and (3) the outcomes of these processes, including the resolution of resistance, changes in community dynamics, and the broader impact on regional integration efforts.

For the qualitative data analysis, an open coding method was applied: transcription, paraphrasing, conceptualization of paraphrases, and deriving categories from concepts. These categories are described and then used to formulate the study's conclusions.

Participants were selected using criterion-based sampling, focusing on regions where resistance was observed. These groups were selected to gain insights from both community members and professionals involved in the reform process.

The study included three men and four women. All the community leaders and regional experts of deinstitutionalisation who were involved in the research had worked through all

stages of the care system reform. To ensure confidentiality, the regions and cities where the respondents worked are not disclosed. Participant information is presented in Table 1.

Table 1. Participant Information

Code	Participant	Type of Community (City/Town/Village)	Years of Experience (Leadership/ Work)
A	Community leader	Town	5 years
B	Community leader	Town	12 years
C	Community leader	Town	6 years
D	Community leader	Town	7 years
E	Community leader	Town	5 years
F	Regional expert of deinstitutionalization	Region consisting of several municipalities	6 years
G	Regional expert of deinstitutionalization	Region consisting of several municipalities	3 years
H	Regional expert of deinstitutionalization	Region consisting of several municipalities including communities B and C	6 years
I	Regional expert of deinstitutionalization	Region consisting of several municipalities including communities A, D and E	7 years
J	Regional expert of deinstitutionalization	Region consisting of several municipalities	4 years

The study’s interviews were conducted between February and October 2023. Respondents were initially contacted via email, which outlined the study’s purpose and duration. Community leaders were identified through media reports covering community protests, while regional reform expert contacts were obtained from the website of the Ministry of Social Security and Labour. Ethical clearance was obtained in 2022 from the Department of Social Work and Social Welfare at Vilnius University.

At the respondents’ request, interviews were conducted remotely via video calls on the Teams platform. The average interview duration was 35 minutes. Before each interview, respondents were informed about the study’s purpose, duration, and confidentiality assurances. Verbal consent was obtained for participation and audio recording of the interviews using a voice recorder.

Results

Education and protest: two sides of one coin

In the following section, strategies of education and protest are presented together, as the absence of timely and accurate information often triggered protests among local

community members. These protests were frequently fuelled by misunderstandings, misconceptions, and fears that could have been mitigated through effective communication. Interestingly, the individuals who voiced these concerns often displayed limited engagement with broader community life, suggesting that their resistance may stem not only from stigma but also from a deeper disconnection or disengagement from the collective social fabric of their neighbourhoods.

In response to the resistance encountered within local communities, the Ministry, bearing the primary responsibility for deinstitutionalisation, augmented its deinstitutionalisation plans with a heightened focus on proactive social campaigns and improved communication strategies. These campaigns aimed “to promote a change in society’s value attitudes, forming a positive society’s attitude to the transformation of the [residential care] system, and to ensure the publicity of the ongoing processes”. In other words, it aimed to address manifestations of public stigma through education and subtle protest, challenging stigmatising attitudes in society.

According to Dirziene et al. (2023), the Ministry frequently utilized ethical and values-based arguments to bolster their position on deinstitutionalisation, representing a delicate form of dissent against prevailing attitudes. These arguments encompassed the concept of a moral obligation to rectify past injustices experienced by individuals with disabilities, particularly the pronounced segregation they endured during the Soviet era. Furthermore, these arguments drew from both international and national legislation governing the rights of people with disabilities. Additionally, the Ministry emphasized the imperative for societal moral advancement, democratization, and the process of shedding Soviet-era ideologies, as discussed by Dirziene et al. (2023).

This narrative resembles the educational approaches to stigma and is supposed to challenge inaccurate stereotypes about psychosocial disabilities. However, they were too general to the members of local communities, whose main concern was about the alleged unsafety in their “back yard” due to relocation of people with intellectual and psychosocial disabilities. As illustrates the following excerpt from an interview with a community leader, people in local communities believe to have reliable information to justify their concerns regarding neighbourhood of people with psychosocial and intellectual disabilities:

I heard during the meeting, they were talking about what I’m telling you now—that they [people with intellectual and psychosocial disabilities who live in the community] drink, that they run around naked in this [name of the care institution], without any control, you know, no one was keeping an eye on them there. Look, we don’t need to bring these people into the centre of town, where kids are walking to school, and then they’ll come out onto the street, you know... well, there are asocial people there. And in our community, maybe the whole centre would just be full of asocial individuals living there. But if it ends up like it was in [name of a small town], where they lived and were falling down drunk on the streets, making love in the bus stops, and so on and so forth, then, well, I don’t even know, honestly, how to put it. (Community Leader B).

Such predominant stigmatising attitudes were insufficiently replaced with factual information. In addition to that, local community members expected accurate and timely

information about what and when is planned for their neighbourhood. Nevertheless, the local and central authorities placed more emphasis on the general aims of the reform and education of the society and provided delayed and scarce information about the concrete deinstitutionalisation plans in the local communities. Research showed, that this approach was one of the main reasons that led to protests:

Well, we found out, I was informed by the residents, clearly there are many people working in [town name], and they had heard, practically when they drove a stake into the plot [*laughs*], then it was heard through [another town name, where an independent living home was built] that such things were coming and it was clear to us already, well, I can't call it a shock like that, but you understand, we would expect such communication between the community and state institutions, so that at least they inform. Of course, it's enough to write there you [community leaders' name], good day there, that's what's going on there, maybe we should have talked. Maybe people wouldn't have reacted like that, but just so you know, when they drive a stake like that, good afternoon, neighbours, and we see who is driving the stake, who is who, everyone immediately attacked. Well, the emotions in the first case were very bad, and we got the information, so to speak, from that stake, driven into the plot. Because there was no more, nor was it made public (Community Leader A).

The deinstitutionalisation expert identified a similar issue of insufficient and contextually relevant information, albeit from a different perspective. Notably, she astutely recognized local community members as the driving force behind the localization of stigma. These community members tend to exhibit a general apathy and disinterest in societal matters. However, when they became aware that independent living houses were being constructed on their street, they displayed intense and aggressive opposition:

It is from that lack of interest, ignorance and lack of understanding that resistance takes place, doesn't it? Because if I don't understand, I wasn't interested, I didn't know what that reform was in general, although in fact six years, it has been talked about in various ways, wasn't it? Both the press and television, you should have heard it somewhere, if you watch news programmes at least a little, don't you? Ahh, when you don't understand what it is, what kind of disability one has, or not, that's just fear, that kind of resistance comes from the fact that, first of all, I'm not interested, I'm not interested in general, what's happening behind my fence, in the ward, settlement, municipality, etc. If I'm not interested, I don't know, there are lots of fears, it's with the whole wave - the neighbour got angry, then I'll be angry too, because I'll be on the same wave, because it's just. (Regional expert of deinstitutionalisation G).

In other words, local and central authorities' ignorance of the importance of stigma has contributed to deinstitutionalisation of stigma. Their efforts primarily focused on combating societal-level public stigma, neglecting the nuanced deinstitutionalisation of stigma at the local level. Consequently, educational programmes initiated by the Ministry yielded unintended consequences, leading to a contrary outcome. Instead of mitigating stigma, these actions sparked protests, effectively mobilizing and unifying even those community members who typically remained passive.

Paradoxically, the rumours about establishing group homes in their neighbourhoods prompted some community members to engage (yet selectively) with the goals and ide-

als of deinstitutionalisation. Concepts such as group homes' proximity to social, health, leisure, and educational services, which are central to the reform, became part of the discourse in these communities. However, rather than fostering support, this knowledge was often reframed as an argument against the relocation of individuals with disabilities. For instance, in the [name of the suburban area], which is located in some distance to the city, resistance was articulated through arguments such as:

Why in the district? Well, [people with disabilities should be relocated to] either another settlement, or even better, [city name], because, you see, here there's nothing to do for them, for these people. In the city, there's plenty to do, there's infrastructure and so on and so on, but here, we're a small community, a small town, we don't really have much here, right? (Community Leader D)

On the one hand, the community members' argument underscores an awareness of the importance of access to infrastructure and services for individuals transitioning out of institutional care. On the other hand, it reveals a deflection of responsibility, with residents suggesting that other areas—especially urban ones—are better equipped, thus perhaps more responsible — to handle the integration process. The repeated emphasis on being a “small community” or “small town” signals a perception of vulnerability and this could explain why residents feel threatened by the introduction of new care facilities, which they may view as a strain on their fragile sense of security.

The resistance to deinstitutionalisation also highlights a broader issue of disempowerment and exclusion in small communities. The lack of constructive dialogue and mutual understanding about the benefits of the reform suggests that local residents were not meaningfully engaged in planning or decision-making processes. This exclusion likely fuelled mistrust and exacerbated resistance, as communities felt that changes were being imposed on them without regard for their concerns or input.

The research revealed few examples of constructive dialogue or efforts to genuinely address local needs. One notable instance occurred in [name of the district], where initial resistance was intense. As one expert on deinstitutionalisation explained:

For example, when this happened in the [name of the] district, right, there was initially a very strong resistance. Later, the mayor himself proposed some solutions, and, well, for instance, how to gain the community's support—they fixed up the street, right? I mean, the municipality itself made investments. It was like showing the residents that a compromise can be found—kind of saying, look, you become more accepting, right? And at the same time, we, from the municipality's side, also do our part, right? (Regional expert of deinstitutionalisation I).

This example demonstrates a reactive approach to resistance rather than a proactive effort to build community engagement from the outset. While the investment in infrastructure was effective in easing tensions and creating a sense of compromise, it also reveals a transactional dynamic — offering material improvements in exchange for acceptance of the reform. This approach, while pragmatic, however, falls short of fostering deeper understanding or long-term attitudinal shifts among community members.

An example from another community provided by another deinstitutionalisation expert highlights the power of inclusive decision-making in addressing community resistance and fostering acceptance during the implementation of sensitive projects:

In the municipality of [name of the municipality], there was significant resistance from the local community after a plot of land had been selected for development. What the municipality did next, and what I personally found very commendable, was organising a meeting to directly engage with the community and understand their concerns. They proposed that the community delegate representatives to a working group tasked with discussing and deciding on the plot's location. And what happened? Once community representatives participated and realized that their voices were genuinely being heard, there was no need to change the location of the plot or look for alternative sites. This is an excellent example of successful community involvement and collaborative problem-solving (Regional expert of deinstitutionalisation J).

By organising a meeting and inviting community representatives to participate in the decision-making process, the municipality shifted the dynamic from confrontation to collaboration. This approach empowered residents, making them feel heard and valued, which likely reduced opposition. The community's realization that their input genuinely influenced decisions helped diffuse tensions and avoided the need for costly or time-consuming changes to the project.

Communities very much needed clarity about who is coming to live there, how life will look, and whether there will be specialists involved in providing these services. This is something communities need to hear: that there will always be someone nearby, a professional, especially in group homes, available 24/7. It's about reassuring them that people with disabilities will receive constant support and assistance (Regional expert of deinstitutionalisation H).

On the one hand, this statement by one of the deinstitutionalisation experts highlights the importance of transparency and communication in facilitating community acceptance during deinstitutionalisation processes. Providing clarity about who will live in group homes, what their daily lives will entail, and, especially – the presence of professionals to ensure support addresses key concerns of the local population, which has occurred throughout most of the interviews. This need for reassurance underscores the fear of the unknown often associated with integrating people with disabilities into residential neighbourhoods. On the other hand, the emphasis on 24/7 professional support also very evidently reflects a perceived tension between independence *versus* oversight in the community's perception of group homes. While the model aims to promote autonomy for people with intellectual and psychosocial disabilities, communities may view this professional presence as a necessary safeguard to mitigate perceived risks. Moreover, the reliance on such reassurances suggests that stigma and stereotypes about people with disabilities persist, requiring structured narratives to counteract them. This highlights the broader challenge of moving from superficial tolerance to genuine inclusion, as communities tend to accept group homes only if they perceive them as tightly regulated and well-managed.

Contacts: superficial 'diplomatic relations' versus actual friendships

From the perspective of persons with intellectual and psychosocial disabilities, the study revealed both positive and negative impacts on their lives. Among the positive outcomes are increased independence, improved physical and mental health, and new opportunities for participation and employment. In some communities, there are encouraging examples of people with disabilities forming amicable relations with their neighbours. However, these interactions often resemble 'diplomatic relations' (e.g., neighbours visiting for coffee and cake before Christmas), facilitated by social workers, or 'barter exchanges' (e.g., assisting neighbours with apple picking in exchange for apple juice), and they rarely develop into personal friendships.

On the other hand, during the relocation process from large institutions to community settings, the opinions of persons with intellectual and psychosocial disabilities were rarely sought regarding where and with whom they wished to live. Corrigan's research (2005) underscores the significant potential for reducing societal stigma by promoting direct contact, thereby fostering greater social inclusion. However, this approach faces challenges influenced by self-stigma, public stigma, and a hostile environment within local communities. In some instances, the initial direct contact involved hate speech from community members (although, over time, this unfriendly behaviour shifted to more positive interactions):

So, as I mentioned, there was swearing, insults, and name-calling — those women [with disabilities] were being verbally abused and mocked, you know, in the stairwell, in the yard, and so on. But, as I said, later neighbours apologized. One of the neighbours, a woman, said, 'Well, now I feel ashamed of how I acted because I realized that these are people, real people, who live among us, right?' (Regional expert of deinstitutionalisation F).

The initial hostility expressed through hate speech and verbal abuse highlights the deep-rooted prejudices and fear of the "other" that can arise when individuals with disabilities are relocated into community spaces. Such behaviour underscores the lack of prior meaningful interaction and the power of stereotypes to drive exclusionary attitudes. However, the later apology and acknowledgment of shared humanity by the neighbour signify the transformative potential of direct contact, as suggested by Corrigan and Penn's (1999) contact theory. Through direct exposure, the neighbour recognized the individuals as "real people," challenging their preconceived notions and fostering empathy. On the one hand, this shift demonstrates that while initial reactions to deinstitutionalisation may be characterized by resistance and hostility, sustained interaction can foster attitudinal change and eventual acceptance over time. On the other hand, this example highlights the significant burden placed on people with disabilities and social workers, who are expected to maintain friendly and exemplary relations while anticipating that hostility will eventually diminish or transform into friendship.

In their daily work, deinstitutionalisation experts interact closely with municipalities, NGOs, and communities to address resistance and stigma while, among their other tasks,

promoting direct contacts between community members and newly relocated people with intellectual and psychosocial disabilities.

It's just that, well, if there's constant communication with the municipality, and if we see that, well, more discussions are needed, right, either to, well, reduce that resistance, right, or with the partners who will be providing group home services, then yes, more time is simply dedicated to that. (Regional expert of deinstitutionalisation I).

While professional interactions with people with intellectual disabilities are welcomed and even facilitated (e.g., workshops, performances), there is a clear reluctance to extend these relationships into personal contexts. Community members rather prefer maintaining a professional distance, limiting contact to controlled environments like libraries, where roles and boundaries are clearly defined, as in the following example shared by one deinstitutionalisation expert:

The community leader works at the local library and helps organize events for people with intellectual disabilities. They come for workshops, put on performances, celebrate traditions like Michaelmas, and use the library for presentations and plays. It looks like everyone is interacting, communicating, and things are going well. But then, news comes that group homes for people with intellectual disabilities will be set up in the community. That same community leader, who works at the library, starts opposing it, saying, "We don't want them here." She even says, "It's fine if they come to visit, but I don't want them living in my village." When asked if there's ever been an incident at the library to justify her concerns, she admits, "No, never." Yet, she still resists. (Deinstitutionalisation expert I).

Thus, the acceptance of people with disabilities is rather context-dependent: while the library is perceived as an appropriate space for interaction, the idea of group homes is perceived with resistance. While symbolic inclusion (participation in public events) is tolerated or even encouraged, genuine integration (living within the community) encounters resistance and this example points to a superficial acceptance and avoidance of deeper relational or structural changes. Moreover, while the community leader has had sustained positive interactions with people with disabilities in the library, this has not translated into a broader acceptance of their presence in the community. This example challenges the assumptions of contact theory, which posits that meaningful interactions can reduce prejudice and suggests that contact alone, without addressing underlying biases and power dynamics, may not be sufficient to foster genuine inclusion.

Furthermore, insights from interviews with deinstitutionalisation experts demonstrate avoidance behaviours, such as community activists' reluctance to visit well-functioning group homes or direct harassment of individuals with disabilities participating in community meetings. These dynamics contribute to the challenge of establishing genuine and supportive interactions between individuals with disabilities and their communities.

Another important aspect is that at this stage of deinstitutionalisation, the role of the major players (Ministry of Social Security and Labour and local authorities) shrinks, and the further responsibility of the success lays on the shoulders of local actors, starting from

administration of care institutions, social workers and ending with people with disabilities. Thus, despite experiencing self-stigma, self-discrimination, self-isolation and low self-esteem (Corrigan and Rao 2012), individuals with disabilities are expected to contribute to overcome the localized stigma by showing themselves as exemplary citizens and sometimes acting as disability rights advocates. This involves managing their home yard and neighbourhood environment ("And for the neighbours, it was like snow again — people with disabilities cleared one path, then another, brought medicine to the elderly during COVID. These people became part of their lives, their best friends" (Regional expert of deinstitutionalisation D), actively participating in city events and meetings with the members of potentially hostile communities (even if it negatively impacts their health afterwards) and receiving guests from the neighbourhood or other communities.

The findings reveal that while encounters between individuals with psychosocial and intellectual disabilities and community members have the potential to reduce stigma and foster inclusion, these interactions often remain surface-level or symbolic, failing to translate into deeper, sustainable personal relationships or broader acceptance. This reluctance to fully embrace genuine integration is shaped by a combination of self-stigma, public stigma, and stigma by association, exacerbated by societal and policy shortcomings. Although such encounters can lead to transformative changes in attitudes over time, the process is slow, cautious, and heavily influenced by external factors such as inconsistent deinstitutionalisation strategies or local tensions.

Conclusions

Research has highlighted protest, education, and contact as key strategies for combating stigma (Corrigan and Penn 1999). Within this framework, Ministry was identified as a primary actor expected to lead educational efforts. The Ministry initiated and advocated for reform especially at national level. However, the Ministry's communication was delayed, abstract, and lacked a localized approach. Educational campaigns emphasizing moral arguments and broad societal values were too abstract for local communities, whose primary concerns revolved around practical issues like safety and integration into their immediate environment. In many cases, failures in communication, or its complete absence, were the primary drivers of protests in local communities. Corrigan's emphasis on targeted, factual education suggests that these campaigns could have been more effective if they addressed specific local fears and provided clear, relatable examples. Consequently, rather than simply being ineffective, these educational efforts often had the unintended consequence of exacerbating stigma and resistance.

According to Corrigan et al. (2001) protest is supposed to suppress negative attitudes and representations of mental illness. The research demonstrate that protest was used to express (instead of suppress) negative attitudes and representations of mental illness. Protests effectively mobilized disengaged community members, drawing attention to local concerns. Community protests revealed deeply ingrained, localized forms of stigma,

where opposition was less about societal-level attitudes and more about perceived threats to neighbourhood norms. The abovementioned Ministry's failure to properly communicate with local communities, consider and appropriately address the impact of stigma on the local level, has led to protests against the relocation of persons with psychosocial and intellectual disabilities. In this context, the protests were not geared towards combating stigma but, instead, served to amplify and reinforce it by specifically localizing and targeting residents of the group homes. At the same time, while protests highlighted gaps in communication, they also pressured local authorities to address specific concerns, such as infrastructure improvements or transparency in planning.

Corrigan and Penn (1999) argue that stigma is reduced when members of society interact with well-integrated individuals with psychosocial disabilities. However, the research highlights a significant absence and avoidance of meaningful interactions between community members and people with disabilities. Negative examples include refusals to visit successfully functioning group homes, verbal attacks on individuals with disabilities attending community meetings, or selective friendliness — welcoming people with disabilities into day centres while opposing their presence as neighbours. On the other hand, people with disabilities are not typically active in seeking contact either, as their mobility is often limited and encounters with community members remain infrequent. This mutual lack of initiative and limited opportunities for contact from both sides results in slow and minimal progress toward meaningful integration.

While initial hostility and hate speech were observed in some cases, structured and mediated contact facilitated by social workers eventually led to shifts in attitudes. Even passive forms of contact, such as living in proximity, have shown potential to change attitudes over time. Corrigan's theory suggests that repeated exposure, even without active engagement, can challenge stereotypes and gradually foster acceptance.

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