

BRIEFING PAPER

Deinstitutionalization in Croatia: A Summary of Open Society Support

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Introduction

Dario is a 34 year-old man in Croatia who has severe intellectual disabilities. He has not developed verbal communication and is incontinent. He is fascinated with strings and when deprived of them he beats himself. Because of this he was physically restrained for most nights and many days in the rehabilitation center where he lived. Dario's life changed in September 2013, when he and two other residents of the center returned to their hometown Pakrac. They live in a house just like all the other houses on the street. They are supported by staff who help them get involved in household chores and activities in the community. Dario no longer spends days and nights in restraints. When his parents visit, they say Dario has more color in his face and that he looks much calmer.

Helping create the possibility for people like Dario to return to communities where they are supported by family and friends is one of the primary goals of the Open Society Mental Health Initiative (MHI). This paper will examine the 17 years of work we have done in Croatia and how it informs our current activities and priorities. By looking back at our activities and bringing them up to the present, we will highlight the challenges and opportunities we face in helping people like Dario end their marginalization, exercise their rights, and lead more independent and satisfying lives.

Overview

Building a new approach to social inclusion in the aftermath of war: Croatia, 1997-2007

The Open Society Foundations' Croatia portfolio capitalizes on a 17-year investment by the Mental Health Initiative. Working with local partners, we have advocated with successive Croatian governments for the social inclusion of people with intellectual disabilities and the replacement of long- stay institutions with community-based alternatives.

Deinstitutionalization and the development of community-based supported housing services for people with intellectual disabilities are not new in Croatia. The work began on a small scale in 1997, as a partnership between MHI and the Ministry of Labor and Social Welfare (now the Ministry of Social Policy and Youth). MHI started this work when Croatia was still rebuilding following the war in the former-Yugoslavia. We believed then that the development of community-based services and advocacy for people with intellectual disabilities needed to occur at the same time that other aspects of society were being rebuilt. If society did not attend to

people with intellectual disabilities at this time, they would be forgotten in institutions and never be a priority.

MHI believed that it was possible to develop community-based services. We wanted to provide an alternative that would highlight how confining people for decades in long-stay social welfare institutions is an archaic way to provide services. We also wanted to highlight how it deprives people of their fundamental human rights. The idea was to establish a cost-efficient model where people with intellectual disabilities could lead dignified lives, and that the government could assume financial responsibility for over time.

MHI's first contact in Croatia was with the Center for Rehabilitation in Zagreb, a large public social welfare institution. Over a two-year period, its director and a number of its key staff were taken by MHI to the United States on study visits to see how community-based services operated. Although, the director and key staff said they believed in "inclusion" they were never able to shed their "us and them" frame. After two years without results, MHI recognized the need to try a different approach. To find new partners, we contacted professor Borka Teodorović at the University of Zagreb's Faculty of Education and Rehabilitation.

The Association for Promoting Inclusion (API)

Seventeen years ago, Teodorović and like-minded colleagues only dreamed of starting deinstitutionalization and advancing a reformed system. They could not conceive of anybody who would support and pay for such work. MHI filled this gap by working with Teodorović and others to create an organization called the Association for Promoting Inclusion (API) in 1997. API focused on releasing people with intellectual disabilities from institutions by creating a model of community-based supported housing that could be replicated in Croatia and beyond.

MHI's first collaborative project with API started in 1998 and focused on a long-stay residential institution, the Center for Rehabilitation in Zagreb. Despite the earlier, frustrating engagement with the Zagreb center, MHI and API were able to rekindle relationships with staff at the center and develop new connections through Teodorović and Zagreb University. These two institutions provided the professional capacity and practical experience necessary for successfully developing alternative services and approaches. Staff received training on community-based service provision, and MHI provided additional expertise from abroad. API then began the deinstitutionalization of several residents. Among the first were a couple, Kata and Bozo, who moved into an apartment in Zagreb and later married. API rented additional apartments, and several more people moved from the institution to the community. Project team members from API and the Zagreb center provided community support for residents. MHI co-financed this program together with the Ministry of Social Policy and Youth (MSPY) for three years, after which time the MSPY took over full financing.

Croatia also institutionalized children with intellectual disabilities, and API established a program of specialized foster family care, which was recognized for its quality by the Council of Europe in November 2000. In addition to services to take in people who were deinstitutionalized, MHI in 1999 supported API in establishing a team of professionals in Bjelovar who began providing community-based services to prevent the institutionalization of people with intellectual disabilities. API then used subsidiaries to establish and pilot at-home support and day programs in Bjelovar and Osijek.

Using the law to gain funding for services

Prior to 2000, Croatia had no specific legislation governing community-based supported housing services. API identified a loophole in the law on residential institutions that enabled it to register its program as a “residential institution” offering services in the community. The law did not specify then that services needed to be provided inside an institution. API went on to successfully negotiate the recognition of community-based supported housing with the MSPY as a government-financed social welfare service for people with intellectual disabilities. It then negotiated a contract with the MSPY and received per capita funding for each person it supported, at a rate 30 percent lower than the average per capita amount the MSPY paid to residential institutions.

After registering the “Home for Independent Living,” API continued to expand supported housing services to people with intellectual disabilities in rented apartments in Zagreb. People lived according to their wishes: some lived alone; others shared an apartment with their partner, or lived in groups of three to five people. API adjusted support according to individual needs and varied it from several hours a week to 24 hours a day. The people supported engaged in activities inside the household as well as outside. Within a few years, API managed to demonstrate that it was realistic and possible to develop quality, cost-effective, community-based services for people with intellectual disabilities.

Sowing the seeds of a self-advocacy movement

Early on in its development as a supported housing service provider, API recognized and understood the importance of listening to the people it supports as a condition for more client-centered, rights-based services. It made self-determination and self-advocacy training available to everyone. Clients were encouraged to form opinions, direct their lives, and have a say in how the service supported them. The people who used API’s supported housing services formed self-advocacy groups. These groups met regularly and learned and discussed their rights, their responsibilities, and the way they wanted to be supported in order to live in the community. As a group, they would discuss issues with the staff of the supported housing service and find ways to improve service delivery so they could live as they wanted. This

environment prompted the formation of the Association for Self Advocacy (ASA), an NGO established with MHI's support in 2003 that is operated by and for people with intellectual disabilities.

ASA members are adults with intellectual disabilities. They fight for freedom of speech, the right to live in the community, the right to vote, and for real equality in society. Many residential institutions engage in the practice of placing every client under plenary guardianship, which strips residents of their right to exercise their basic rights. ASA supported API's lawyer in initiating seven court cases on behalf of its members who wanted to marry, but could not without the permission of a judge because they had been stripped of their legal capacity. Six of the cases ended successfully with the judge granting permission to marry. One judge, however, denied permission, stating that the applicant, due to her disability, could not "understand the nature of love." Recently, in part due to ASA's efforts, Croatians with disabilities enjoyed an important civil rights victory: the government aligned its voting legislation with the requirements of the UN Convention on the Rights of Persons with Disabilities (CRPD), allowing all citizens, regardless of whether they have legal capacity, to vote in elections.

Building the capacity of others and going to scale

While still a young organization, API has recognized the importance of developing a relationship with the Union of NGOS of Parents of Children with Intellectual Disabilities. API knew that working with this already-established network would help spread the idea of inclusion, and would lay the ground to identify and support local individuals and/or NGOs to develop and provide community-based services. With MHI's support, API has made focused efforts on disseminating the models it has established. API identified motivated individuals and groups and supported the establishment of a number of subsidiaries in Croatia. It provided training and technical assistance to these subsidiaries and to other NGOs interested in developing community-based services. It worked side-by-side with these partners to develop supported housing services, enabling more people to leave residential institutions. Today, these services, developed by API subsidiaries in six cities, along with those developed by other organizations in several other locations, support over 350 people with intellectual disabilities, autism, and mental health problems. All of these services are now government contracted and financed.

An initial attempt to close a large institution

Once we felt the infrastructure was in place and that we had established significant allies and connections, MHI and API in 2005 carefully planned their next major initiative: closing the Center for Rehabilitation in Stančić, the largest residential institution for people with intellectual disabilities in Croatia. MHI and API negotiated with the MSPY, and elaborated a detailed implementation plan. They also financed a cost-benefit analysis at the MSPY's request, to show that community-based services would be cost neutral in the long term. The concept

drew on available evidence from other countries, built on the practical experience of people who had done this before, and brought to bear MHI's considerable energy and resources. Taking an entire institution and transforming it into a community-based system was a bold plan. It had the potential to produce a much-needed example of what was required across all such institutions in Croatia. At the European level, MHI and API promoted the MSPY's leadership and helped build its profile as a body willing to tackle one of the most pressing social and human rights problems of the day.

With all the pieces in place, MHI proposed to provide the \$2.3 million necessary to cover the transition costs of transforming the Stančić center into a community-based service provider. After two years of negotiations, the deal broke down. The MSPY did not have the genuine political will to take this significant step forward once it realized how complex it was. It also underestimated how much resistance it would face from the rehabilitation center's leadership and staff. Additionally, HDZ government in power at the time was unfriendly toward the Open Society Foundations. It was one thing for the MSPY to provide some financing for small-scale community-based services, but closing the Stančić center was entirely another. The MSPY counter-offered to invest the proposed funding in building additional space in a different institution. This was a compromise MHI could not accept: institutions, even if they are newly built, can never provide the liberty and choice that people with intellectual disabilities are entitled to, and can only experience in the community. By 2007, MHI and its partners had helped many people leave institutions, yet our efforts to close a large institution had yet to materialize.

Leveraging the Croatian experience in the region

In response to the setback of not transforming the Stančić center in Croatia, MHI asked API to support building the capacity of partners that wanted to develop community-based services in other countries of the region. API assisted numerous organizations in Bosnia and Herzegovina, Georgia, Kosovo, Macedonia, Moldova, Romania, and Serbia. API became a sought-after resource for training and helping build technical and organizational capacity. API also established itself as a prominent force in policy-based advocacy at the local, national, and European levels. It regularly comments on draft legislation and regulations, advocating for the development of person-centered services. In 2006, its advocacy efforts resulted in the formalization of the service of organized housing as a separate service, distinct from institutional placement. At the European level, API provided feedback on Croatia's periodic progress reports to the European Commission during the EU accession process. Its continuous advocacy and status as a "thought leader" in this field have had a significant impact on deinstitutionalization in Croatia.

A New Window of Opportunity to Close Large Institutions

CRPD ratification and EU membership create new possibilities

Croatia's accession process to the European Union created new incentives for the government to adopt progressive policies and opened a new window of opportunity for deinstitutionalization. In 2007, Croatia became the third country in the world to ratify the UN Convention on the Rights of Persons with Disabilities (CRPD) and its Optional Protocol. Pursuant to Croatia's ratification of the CRPD and the adoption of a national strategy on equality for persons with disabilities, the MSPY adopted a national plan on deinstitutionalization and transformation of social welfare institutions. The goal of the plan was to advance deinstitutionalization, and transform long-stay residential institutions into community-based service providers. This goal is also reflected in the Joint Inclusion Memorandum on Social Inclusion, which was signed by Croatia with the European Union as a commitment in its EU accession process. With MHI's support, API and ASA were both actively involved in advocating for these progressive policies in Croatia and at the EU level.

In July 2013, Croatia became the newest member of the European Union, which has also ratified the CRPD. The European Union has a range of policies that aim to ensure respect for human rights, emphasizing the importance of equal opportunities and full social inclusion. It also has an obligation as a donor to ensure that European taxpayer money is not invested in a manner that contravenes its commitments and results in discrimination against any European citizen. Croatia is now eligible for EU funding, creating an additional incentive to comply with both its own and European-level human rights commitments.

A tripartite alliance to deinstitutionalize two large institutions

Latching onto a unique opportunity to push deinstitutionalization forward, MHI decided to reengage with the government. Together with its long-term partner API, the Center for Adult Education Validus, and the MSPY, MHI established a tripartite alliance and designed a five-year project aimed at deinstitutionalizing over 400 people with intellectual disabilities from two large residential institutions. The memorandum of understanding sets out the responsibilities of all parties and establishes oversight mechanisms for the project.

The Rehabilitation Center Zagreb and the Rehabilitation Center Stančić, whose attempted closures were unsuccessful in 1997 and 2006 respectively, were selected as they continue to be the backbone of the institutional system in Croatia and represent two very different

models. Stančić is the largest residential institution in Croatia, located in old stable buildings in a rural area close to the capital. It supports over 340 people, and is seen as a challenge to transform. The center in Zagreb has over the years developed a network of community-based day programs at its own initiative, and the majority of its over 600 clients live with their families. Long-term residential services are provided to 150 people in five central locations in Zagreb. The center in Zagreb was chosen because it was already well on its way to becoming a community-based service provider. With this new endeavor, MHI aims to capitalize on years of successful demonstration projects and “jump-start” a systemic and irreversible shift from institutional to community-based services.

Bridge funding and technical assistance to government

In the process of transforming care from an institutional to a community-based model, transition/bridge costs are generated by the need to run both the institutional and the community-based services as residents make the move to the community. While MHI and the Croatian government share the view that the core costs of deinstitutionalization are a government responsibility—as evidenced by the fact that 90 percent or almost \$30 million of the cost of this project is borne by the government, the Open Society Foundations are providing the critical transition, or bridge funding. Open Society’s contribution of \$3.3 million over five years comes with the understanding that when this funding ends in 2017, the MSPY will take over full financing responsibility for the services, by redirecting funding from both centers to the community-based services.

Transformation of the two institutions does not mean simply physically relocating the residents into housing in the community. It involves a real transformation in the way the institution and its staff work. Because of the government’s relative lack of experience and capacity to develop community-based services, a unique feature of this initiative is that the MSPY can rely on two MHI-supported NGOs as training and technical assistance partners who have extensive experience in disability, deinstitutionalization, and quality assurance. The training and technical assistance provided by API (in developing community-based services) and Validus (staff training) focuses on the provision of person-centered services and on the active participation of people supported in the life of the local community. The involvement of these NGOs, in our view, is key to the success of this initiative. In addition to the theoretical training and workshops to show staff how people can be supported in the community in vastly different ways than is possible in an institution, the practical, on-the-job training that happens in community homes helps staff understand their future roles and responsibilities. By involving local partners as key stakeholders, MHI also promotes the active engagement of civil society as a force to ensure that reform is implemented and sustained.

Documenting the process

Documenting this complex process is an important part of the initiative, and the use of audiovisual material is a particularly effective way to record not only procedures, but the very significant human rights aspect of the reform. MHI is supporting Gral Film, a Croatian company experienced in making films about people with disabilities, to document the current large-scale deinstitutionalization effort. Gral Film's work questions the barriers to social inclusion that people with intellectual disabilities face. It also highlights how they can realize their right to live and work in the community and find their place in society. Gral Film focuses on people who strive to live like all other citizens, and the company is committed to making these efforts visible to the public. The materials Gral Film will produce will contain many important lessons for future efforts to replace institutions with community-based services. They will be of particular relevance for efforts to replicate the models developed in Croatia, and to advocate for large-scale reform in the region. The films will also bring to life the people behind the process by documenting the attitudes and opinions of key stakeholders, including the concerns and hopes of parents, residents, and staff as they participate in transforming the system.

Goals and expectations

This initiative will achieve the following:

- Over 400 people who now live in institutions will have a significantly improved quality of life, and will finally be able to realize their right to live and be included in the community with support.
- The more than 300 staff members of the Zagreb and Stančić centers will be retrained and able to run a range of community-based support programs including housing, leisure time, employment, and occupational activities. Their working conditions will be significantly improved as they are redeployed to work in community-based services.
- The MSPY will have a sustainable model of community-based services that it can replicate across its other social welfare institutions.
- The methodology of the process of deinstitutionalizing the two centers will be documented and available for use across other institutions.

Achievements to date

Since it began in mid-2013, the initiative has had several significant accomplishments:

- The two institutions have released close to 100 people and these individuals now live in homes in the community, either with foster families (children), or in homes with their own families.

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- A well-established self-advocacy group is providing assistance to people who have recently been deinstitutionalized to develop their advocacy skills.
 - The Zagreb and Stančić centers have staff trained to provide supported housing services and have established day centers where people who cannot work on the open market are occupied.
 - The MSPY has obtained four state-owned homes that it has provided for use as community-based housing free of charge.
 - The Croatian Employment Service, in the framework of the government’s “active employment” policy, is providing funding for the payment of salaries for under-employed groups for at least one year to work in community-based services, reducing the overall cost of this initiative.

Challenges, Risks, and Next Steps

The consequences of austerity

Most of Europe continues to reel from the effects of the 2008 economic crisis, and Croatia is no exception. In this context, the level of the Croatian government’s investment in this initiative is particularly striking. The country’s unemployment rate is over 20 percent and the government continues to cut spending throughout all sectors, with the social welfare field being particularly hard hit. Yet the government has not cut funding for services for people with disabilities and it continues to demonstrate the political will to reform how social welfare services are provided. A worsening economic situation might threaten this status quo, and the MSPY is recognizing that it needs to reevaluate the per-person funding for community-service providers in the face of significant increases in the overall cost of living.

A changing political landscape?

Given how much successful deinstitutionalization depends on the Croatian government’s political will, another risk is if a new government with less commitment comes to power. Croatia’s current government is in the middle of its four-year mandate. While there has been some talk of early elections, this seems unlikely at this time. MHI and its civil society partners are mitigating risks by keeping up the pressure on the MSPY to stick to the agreed implementation timeframes. If the work proceeds according to plan, the deinstitutionalization process will be too far along for any government to abandon it. The

Croatian government can cite it as a major vehicle for reform when various international bodies raise questions about the country's compliance with some human rights obligations.¹

Confronting inertia

A significant challenge to deinstitutionalization is related to the profound changes at play. When it comes to change, people tend to be resistant to it, rather than advancing or supporting it. The cost associated with operating the status quo becomes the justification for maintaining it, even if it was a poor solution in the first place. Change for institutions is similar. It is often easier to maintain them despite their flaws than to develop alternatives. The status quo is already in the budget, even when we know that alternatives are better and more cost-effective over time.

Winning over two key constituencies: staff and parents

Staff in institutions tends to be skeptical of a community-based system that requires them to examine their own prejudices and rethink long-established practices. They often cannot imagine their roles in a different system. Some research shows that for staff, the closure of an institution is similar to dealing with a death. The initiative is facing some significant and familiar resistance from Stančić center's staff and management. While the intensive training available to staff helps them better understand their future roles and responsibilities, the lack of clarity as to what will happen and how it will affect them in the long term is causing resistance. This is understandable, as people are afraid of job losses or pay cuts, and the MSPY is not yet in a position to provide them with clear information as work is still underway on determining service cost standards. While this matter cannot be ignored, it is worth noting that staff who have redeployed to the first community-based housing services are very positive, and have been helpful in reducing the resistance of their colleagues. Also, unlike a decade ago, the government's commitment and political support appear to be unwavering and are anchored in EU commitments and the law.

Parents and guardians of the people residing in both institutions also show resistance. Small groups of parents who oppose the transformation have advocated for the reform to slow down, or even stop. This type of resistance is very common in deinstitutionalization efforts, as parents often fear how their child will cope in the community and have difficulty accepting that

¹ The Committee for the Prevention of Torture (CPT) visited Croatia in September 2012. In its report, the CPT noted as highly problematic that numerous Center Stančić residents are restrained in straightjackets, and by being strapped to beds and wheelchairs. In its recently published response to that report, the Croatian government underlined that this Open Society Foundations-supported project is being implemented, and that the Stančić center is not accepting new admissions.

community life is possible for their child, since they were not able to provide the care required to make that happen. All these years, their family member received care in the institution from some of the very staff members who are now resisting the move to the community.

Much of the opposition is also due to the lack of information concerning the process. In these cases, the MSPY bears some degree of responsibility for not communicating as clearly as possible to the institutions about what, exactly, the initiative involves. To mitigate this risk, MHI is working with the MSPY to develop targeted messages for these audiences that provide clear and relevant information, but much remains to be done. Our experience with parents shows that they need time, and they need to see other residents make the transition. Time and examples of other residents successfully living outside their former institutions have helped transform many initially skeptical parents into some of the fiercest advocates for community living.

Building on the Stančić and Zagreb experience and leveraging the European Union

Knowing that significant additional resources in the form of Structural Funds will soon be available, the MSPY is already planning their investment for further reform. Croatia has an estimated 5,000 people living in 114 long-stay social welfare institutions that are waiting to be transformed. Most of these institutions have significantly smaller residential capacity than the centers in Stančić and Zagreb and will be easier to transform. The legal and financial framework we are developing for the centers in Stančić and Zagreb, and the documentation of the deinstitutionalization process, offer a roadmap for replication. API is already bringing what it has learned to an EU-funded project that will support the social welfare sector in the deinstitutionalization of social services. API is the lead local partner for the international consortium that is implementing the project, which will help 26 institutions develop deinstitutionalization strategies and proposals for the soon to be available European Structural Funds.

Replication beyond Croatia?

While social welfare systems differ from country to country, the big ideas that this project operationalizes—the development of quality, person-centered, community-based services and policy and legislation that is aligned to support the new system—could be adapted to other contexts outside Croatia. The outputs, such as training materials for staff, protocols for relocating residents and helping them adjust to the community, contracting with community-based service providers, and monitoring and evaluation frameworks can be used in other deinstitutionalization efforts. We are also exploring ways to profile and establish Croatia for its best practice in this field at the EU level, as a way to both cement EU buy-in for this model and to generate interest in other countries.

The most important challenges to deinstitutionalization, however, tend not to be technical, but political and human. We have learned many lessons and they have helped us identify the preconditions that must be present for successful deinstitutionalization efforts, including:

- Political will at the government level, championed by a handful of advocates and translated into national commitments (e.g., CRPD ratification, laws, national action plans, etc.). These elements create a solid foundation on which to build that cannot simply be discarded if the government changes.
- Incentives for the government to respect the human rights of people with disabilities. The EU accession process and the prospect of access to EU funding played crucial roles in the Croatian case.
- Contextualized know-how and committed technical-assistance providers able to support government efforts for which they do not have in-house capacity (the U.S. context for visits was seen as too different).
- Cost-effective, efficient community-based models that can be replicated on a larger scale, and exist within a legal framework.
- Strong civil society partners that will relentlessly advocate for and support change, holding government accountable.
- Continuous and strong engagement with the institution staff and parents involved in the reform process. These two constituencies are directly affected and often fearful and resistant to change. But they are absolutely essential for the successful inclusion of people with disabilities in the community.

All of these elements are now present in Croatia. We have developed them by using a multi-faceted strategy, seizing political opportunities, and adjusting our approach as we learned. We are now poised to have the Open Society Foundations' 17 years of persistence and investment pay off with enduring reforms that reflect our commitment to the rights and dignity of people with intellectual disabilities.

Additional Information

Photo Slideshow

<http://www.opensocietyfoundations.org/multimedia/people-developmental-disabilities-living-everyone-else-does>

Video

Right to Work: Voices Grantee Spotlight

<http://www.opensocietyfoundations.org/voices/when-work-more-just-job>

Right to Vote: Voices Grantee Spotlight

<http://www.opensocietyfoundations.org/voices/why-am-i-different-disability-and-right-vote-croatia>

Universal Design: Voices Grantee Spotlight

<http://www.opensocietyfoundations.org/voices/new-day-institution-community-zagreb>

The Right to Live in the Community: Voices

<http://www.opensocietyfoundations.org/voices/community-not-confinement>

Documenting the process

<https://www.youtube.com/user/GralFilm>

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The Open Society Public Health Program aims to build societies committed to inclusion, human rights, and justice, in which health-related laws, policies, and practices are evidence-based and reflect these values. The Program advances the health and human rights of marginalized people by building the capacity of civil society leaders and organizations, and by advocating for greater accountability and transparency in health policy and practice.
