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TOGETHER
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transition in social care

PROCESS OF DEINSTITUTIONALISATION

Analysis of the situation in the Czech Republic

Content

I. How is Deinstitutionalization conceptualised in the country

(How it is where, how DI is understood, what is wrong with the current situation, why changes are taking place, what they are aimed at - the purpose of DI). It is also possible to draw on descriptions and analyses that have already been prepared by other actors in the country).

A short excursion into the development of the social care system for people with disabilities in the Czech Republic, which influences the current situation:

People with disabilities were perceived as having long-term illnesses. As people whose disability deprives them of the ability to exercise their own will, to make decisions about the shape of their lives and to exercise their rights. Related to this was the tendency to isolate such people from society and to place them in closed institutions with large capacities - tens to hundreds of places. Historical buildings (castles), large church buildings, in the outskirts of villages were often used for the establishment of social care institutions.

Institutional care was conceived as protection of clients from the demands of the outside world with a fixed regime, the person was the object of care. People lived in an environment with minimal privacy (multi-bedded rooms - even with 18 places), toilet and bathroom facilities were located in corridors, shared by many people, without ensuring intimacy. The institutions were primarily for people of the same sex. Regimes of care were prevalent (designated time for waking up, eating, resting and working, hygiene, sleeping...) and group activities (group games, group walks, group hygiene, group ownership of clothes issued by staff, shared spaces...). Few people had the opportunity to move outside the walls of the institution (those who did not even need care), otherwise everything took place inside - including medical care, education, work). The social ties of these people were often broken. People had minimal opportunity to make decisions about the shape of their lives, they did not take responsibility for themselves. Their lives were controlled by others; people became dependent on service, on authority. People were unlearned in normal ways of acting in areas of life, the artificial environment caused unusual reactions of people to usual situations. Care was provided mainly by medical staff, in a paternalistic way, in a complex way, leaving no room to address the individual needs of people.

Until 1989, social services in the Czech Republic were provided by the state and consisted mainly of a system of institutional residential services for people with disabilities (social care institutions) or for the elderly (retirement homes). Outreach and outpatient services were marginally represented in the system.

Principle - Man adapts to the system.

After the societal changes and the fall of communism in the Czech Republic, with the development and activity of non-governmental non-profit organizations, space began to be created for solving the unfavourable situation of people more according to their needs, the development of missing forms of social services that could complement or replace institutional services (field and outpatient services). With the development of the emphasis on human rights in general, the inadequacy of the provision of care for people with disabilities received more attention and a discussion began to develop that although people with disabilities have declared rights, they are not able to fulfil them in practice. Initially, the initiative for change was isolated and in the hands of the directors of social services themselves, but later changes began to take place in a more systemic way, including through the involvement of some regions in the Czech Republic (part of the public administration), to which the establishment of the largest institutions for people with disabilities passed from the state in 2003). Later, the evolution in approach was also reflected at the legislative level. In 2007, a new Act on Social Services came into force, which changed the system in place until then. It defines conditions in social services (principles in social services linked to individual needs of persons and protection of their rights, defines types of social services, obligations of social service providers and requirements for their quality, financing system and competences of individual entities, etc.).

Strategies have been adopted at national and local level to support transformational steps to ensure support for people in the community, and a number of support projects are being implemented.

II. Current situation

There are services supporting the life of people with disabilities in the community, whether it is field, outpatient and community residential social services (newly established on the basis of the needs of citizens in the region or as an output of the transformation of the original institutional facilities), follow-up activities are implemented to ensure that people use mainstream public services, and more attention is given to the support of informal carers. However, there are still many people living in institutional services that are in the process of transformation to varying degrees (some have not even started or only formally) and the state financially supports the maintenance of these institutional services in addition to the transformation. The situation is not stagnating, the transformation activities are continuing, mainly as a result of the social policy implemented by the regions, but differences can be seen from region to region.

Deinstitutionalisation is a process that aims to enable people with disabilities to live in a mainstream environment and in conditions comparable to those of other citizens of the same age. Deinstitutionalisation involves two processes. The first is to create the conditions for these people to be adequately supported (either through a network of targeted social services or with the involvement of informal support, e.g. from relatives, the community). That is to say, to enable people to use services in the community according to their needs and to be part of society, to remain in their natural environment and to avoid the institutionalisation of other people. The second process is changes to existing institutional services - transformation of institutional residential services into community-based services.

The essence of the changes are opportunities for people with disabilities to make decisions about the shape of their lives, in ordinary life situations, to exercise their rights, and to be supported to be independent of others.

Principle - The system adapts to the person.

Transformation is the change from a specific large-scale residential service for people with disabilities to housing and support in a mainstream setting. It is the process of changing the management, funding, training, location and form of social service provision so that the end result is to support people with health disadvantages in normal living conditions.

Transformation is not an end but a tool for change. The process of transformation is part of the wider process of deinstitutionalisation.

In 2009, the first criteria were adopted to define the differences between institutional and community social services. They underwent their latest revision in 2022. **The criteria for community service, transformation and deinstitutionalisation** set out the maximum capacities of residential and outpatient social services and their design, principles. For example, for people with the highest level of support needs, this is housing for a maximum of 18 people, but so that they live in a minimum of three households, in single or maximum double rooms. For people with lower support needs, the housing capacity is 12 places in total, with a maximum of 4 people in each household. The household is in the form of an apartment (living room, kitchen, sanitary facilities), the housing is in a place with normal amenities, in a normal development in the village, with the possibility to use all public services, etc.

Over the years, there has been a gradual reduction in the capacity of residential institutional services and an increase in the number of places in community social services for people with disabilities. This has been influenced by transformation processes, but also by the promotion of other forms of support networks that allow people to move beyond residential services. Thus, there are changes in the structure of the social services network as well as in the quality and conditions that support people's everyday lives.

The available sources show a trend, with data from 2011 showing that 15% of people were living in non-residential services and by 2021 this was 26%. Despite this, there are still many people living in substandard conditions. There is considerable variation in access and the situation in the different regions of the country.

As outreach and outpatient services, which can be an alternative to residential services, become more available in the overall service network, so the participation of other actors in providing support to people is also increasing. This is also due to the greater support for carers than was previously the case (respite services, use of care allowances, health and social insurance for carers). However, caring for a person with a high level of support needs at home is still both costly and demanding, depending on where the person lives and what other follow-up services are available.

The first analysis of institutional social services was prepared in 2013 and mapped the situation on an almost nationwide level (outside of the Capital City of Prague), which differentiated residential social services for people with disabilities into services in the community and services of an institutional nature. At that time, residential services represented almost half of the total number of monitored services, approximately two-fifths of services were provided in the field form and less than one-third of services were provided in the outpatient form. The focus then shifted to residential services for people with disabilities (homes for people with disabilities, special needs homes, sheltered housing and weekly residential homes). Of the 639 services of this type, 544 (85%) were residential.

A total of 20 275 people used institutional services. Of this number, 1045 were under the age of 18.

Source. Institutional Social Services in the Czech Republic, National Centre for Support of Social Services Transformation, 2013. Available: celorepublikova-analyza.pdf (trass.cz)

The current situation is described e.g. by the following source: part of a report to the European Commission on the Czech Republic: REPORT ON THE TRANSITION FROM INSTITUTIONAL CARE TO COMMUNITY-BASED SERVICES IN 27 EU MEMBER STATES. By Jan Šiška and Julie Beadle-Brown, 2020. Available: eeg-di-report-2020-1.pdf (jdicz.eu):

Adults with disabilities

- There has been a 10% reduction in the number of institutions and a 30% reduction in the number of people with disabilities living in institutions between 2007 and 2018.
- 1,563 people with disabilities have left institutions between 2014 and 2018.
- 16,000 adults with disability remain in institutional services.

In 2018 there were 11,999 beds (with 11,182 residents) in residential care homes, most of which were in one of the original 204 residential institutions, now called "Homes for persons with Disabilities". This was a reduction of 26% from the capacity in 2007 (15,925 beds, with 15,925 people living there). Ten of the original 209 institutions have been closed since.

Including children with disabilities

- The number of children in residential institutional care in Czechia decreased by almost 29% between 2008 and 2018 (from approximately 10,500 to 7,500).
- For children with disabilities, the reduction was 46% (from 1,063 to 355).
- At least 7,500 children still remain in institutions.

A. Who is involved in providing support to people and their responsibilities - the system, management and funding of support to people.

In terms of principles, the system of support for people with disabilities is set up in an integrative way. The Czech Republic has adopted into its legal system a number of international treaties enshrining the right to equal access and opportunities for all persons and the right to self-determination (e.g. the Charter of Fundamental Rights and Freedoms, the International Convention on the Rights of Persons with Disabilities, the International Convention on the Rights of the Child). National legislation enshrines, inter alia, that everyone has the right to live in the least restrictive environment. However, the right to independent living is not actively enforced, and depends to a large extent on individual providers or even commissioners of social services.

Financial and material assistance from the state plays an important role in the inclusion of people with disabilities. There are a number of tools available to compensate for disabilities from public funds - e.g. aids, special cars. There is also a financial instrument - a social benefit, which is provided to people according to their level of dependence in order to access social services ranging from 35 - 800 Euro per month (which represents the possibility to purchase regulated social services ranging from about 6 - 130 hours of care). The beneficiaries of these funds are the persons in need of care, who can decide for themselves in what form and from which provider they will receive the service. If a person with a care need decides to ask for support in a natural environment from another natural person (they do not have to be family, they do not have to live together in the same place), the care time is counted as work for the purposes of a future old-age pension. Any remuneration is at their discretion.

Ensuring networks of professional social services is the responsibility of individual regions - regions that identify needs and set up appropriate social services. In the long term, the development of field and outpatient services is preferred. All providers of social services must meet material, personnel and qualification requirements. This is a state-regulated area. The selected entities conclude a public service obligation contract with the regions and receive a financial compensation on this basis. Social services are financed through multiple sources. Funding for the provision of social service networks is provided by the State to the regions. Services are also co-financed by the regions and local authorities, but the amount is entirely at their discretion and goodwill. Especially in larger cities, there is competition between providers and the user can choose some services at his/her own discretion.

B. Specific in-country experience and practice with the change process, DI:

- What has been done and with what outputs

See above and below

- **What thrives in the whole process of change**

- National strategies and the possibility of project activities that support change

- The structure of the social services network is changing, services are more responsive to how much a person needs support and in what ways. Moving people away from residential services when they don't need them.

- Greater availability of needed services for people in the regions.

- Transformation of institutions and leaving unsuitable premises. The experience of abandoning whole large buildings, mansions.

- Experience of good practice and sharing it. Examples of both good and bad practice are identified.

- There are methodologies and recommended practices on how to implement the transformation process and they are linked to all stages of the change process.

- There are topics in which actors need to be educated and there are already more people with experience who can act as educators (including people who have previously lived in an institutional service themselves). Support for service workers in many forms (on-site consultation, training to understand, internships, examples, methodological guidance, etc.)

- Greater participation of the people themselves - they are heard more, more emphasis is placed on being part of the action, sharing people's stories themselves, self-advocacy. People are more involved in mainstream activities than before, using public services, more people in paid employment.

- Representatives of local governments, municipalities where community services were established, are willing to transfer their experience. So do the carers of people who were initially afraid of change.

- Risks in service transformation and measures to avoid or eliminate them are identified.

- 20 years of experience in different regions - these are not just "swallows" (isolated cases).

- Fewer people say out loud that people with disabilities should live in institutions (even if they think so :). It is not desirable (though still possible) in the context of social policy principles.

- The public are more used to their fellow citizens, people with disabilities are citizens and more part of local communities

- The existence of support organisations for people with disabilities to address their situation in related areas of life (employment, advocacy).

- Changing the environment and conditions for people with "physical" disabilities - they are hardly found in institutions anymore and live with support in the mainstream community.

C. What is not working

- People are still being admitted to institutional services. It's not a stop state. There are still institutions and many people still live in them.

- DI is not a priority for the state in supporting people with disabilities and is lengthy. The state still financially supports the sustainability of institutional services - operationally and through humanization (humanizing conditions), but this does not address the nature of inappropriate spaces and slows the process of change.

- It is possible for more inpatient services to emerge if they meet the statutory conditions for registration.

- Children with disabilities still live in institutional services.

- Quality control of the social services provided is not in practice linked to unequivocal change (denial of people's rights, especially in institutional services, is still possible, changes are lengthy, often linked to the decision of the founder, who may not be willing to address the situation).

- If the founder or the management of the service is not convinced about the transformation of the service, the situation stagnates or there are slight shifts.

- Half-hearted solutions are mistaken for service transformation (some people leave the institution to go elsewhere, the rest stay; small houses around the original large service in an unsuitable location; creating small institutions by transferring institutional elements in the approach to people, etc.).

- People's needs and disadvantages are not sufficiently mapped.

- The people involved are not routinely involved in decision making.

- Some of the people living in residential services overuse the support system and are not supported by staff to be more independent and self-reliant, taking ownership of their own decisions in ordinary situations.

- Workers in residential services often have the idea that living in a normal environment is "only suitable for some" (people with low levels of support needs), and for people with high levels of support needs they see only residential services as a way out. Similarly, they often see it as inappropriate for older people to move into community services.

- If service staff are not convinced of the changes, they will not convince/support the person.

- Some staff find it more comfortable to work in a large facility where they share responsibility and care regimes are set up, rather than providing individual support to people in a smaller service and being held accountable for their way of providing support.

- Social workers in residential services often do not have the space to do social work, but rather perform social administration.

- The interconnectedness of the solution of a person's adverse situation with the participation of all relevant actors is not common (person, service, guardian, possibly psychiatrist, doctor, school, others...).

- The professional community is not always in favour of change (even from among guardianship judges, forensic experts, doctors, post-acute physicians...).

- Public guardians, even those close to the person, do not always act in the interests of the person and according to their abilities, and intervene in areas of the person's life even in cases where it is not their place to do so.

III. What tools are available in the country

Scale: (1) - functional, (2) - less functional, (3) - not functional

- Legislation and national strategies that imply the need for change and the DI process to enable people with disabilities to live in normal conditions (2).
- Targeted support for social inclusion from European resources (1).
- Project activities supporting the transformation of institutional services in general- in principle (1). If the founder or management of the service is not motivated to implement the change, the activities miss the effect: (2-3).

- Methodologies and manuals supporting the process of changing institutional services - publicly available for interested parties, which have been produced as an output of many projects of various entities. From assessing the needs of people, describing the transformation process in steps and its risks, to the topic of service provider responsibility and guardianship, supporting the employment of people with disabilities. (1-2) depending on the nature of the methodology and the time when it was created.
- Collections of people's stories, stories of transforming services, including analysis of outcomes over time. Outputs from conferences, etc. (1-2)

- Roundtables on a specific topic, thematic conferences (1)

- Personal sharing (1). Preferably one who is in the same role, sharing their experience to people with the same role: person with experience - person, director - director, guardian - guardian, mayor - mayor, social services worker - social services worker, etc.

- Internships (1!).

- Training, support systems for workers leading to understanding the meaning and equipping with competences (1-2).

- Consultation on targeted topics and on-site support. (1).

Identification of what partners would need - description of needs from the perspective of people with disabilities, from the perspectives of organisations, service providers

From the perspective of people with disabilities

- Having the opportunity to live in a mainstream environment with appropriate support.

- To have the opportunity to take responsibility for oneself.

- Lacking their involvement in making decisions for themselves. To focus more on mapping their needs and adversities and to seek with them a pathway that enables them to live a normal life.

However, this requires the competence and insight of support persons and social service workers. To be the subject, not the object of support. They need workers who respect them, who try to solve life situations together with them, who know how to work with risk, who always support the person in communication (also through forms of AAC), so that the person can express his/her will, experience ordinary situations.

- Support in exercising their rights. Support in managing conflict situations with other institutions - school, health care..., with guardians, etc.

- Not to talk about them without them, even on professional platforms (conferences, etc.).

From the perspective of organisations, service providers

- Legislation that will clearly prevent the institutionalisation of other people.

- A declaration by the founder of the need for change and then its support.

- Staff who understand the purpose and need for change, the process of transformation and its purpose and manifestation in the life of a person with a disability.

- Staff who have the knowledge, competence to guide service users through the change and support them in their independence and journey towards living in normal circumstances.

- Staff who recognise that they "work in people's homes and not have people living in their homes".

- A staff structure that meets the needs of the people who use the service.

- The opportunity to share needs, concerns, problems and seek solutions (consultative support, passing on examples of practice - placements - as appropriate...). I.e. also to know that some issues are addressed by other providers and to know where to go for support.

- Decide to change and persevere. Some changes are still lengthy and tied to finances, however much can be done in an existing service and by changes in approach without major demands on money.

IV. What is the experience of active participation in change by people using the service, their relatives?

- People

So far in the Czech Republic, in the transformation of the original institutional services, direct active involvement of people is insufficient, especially in the initial stages of change. People with disabilities who live in institutional services are not automatically part of the decision-making process; the degree of their involvement is very much linked to the insight of the competence of the staff of the service. Yet, as experience grows and services transform, a shift can be perceived.

People who use residential services are often fearful of change, they have no idea of the shape of other lives, they have learned to hand over responsibility for themselves to others, they expect the service to do things they could do themselves. Staff support is needed to ensure that people are an active part of what is happening and that changes in their lives occur in a way that is safe for them and in line with their needs.

Once people move from an institutional setting to another service in the community and have more individual support, they acquire new skills and are more of an actor and part of the action. There is also a growing possibility that some will leave a residential service, albeit in the community, as appropriate and continue to live with only the support of an outreach service or informal support. And they will be more active on this journey than before.

A related issue is that some people are willing to share their story and compare the shape of their lives when they lived in residential care and now. Thus, people with disabilities tend to be in the role of those who share their story (in talks, conferences, meetings...), educators, doing client audits, being self-advocates.

In municipalities where social service networking (planning social services according to the needs of citizens) is in place, they can get involved in the process themselves or with support and transfer their needs there, but in practice this is rare.

- **Loved ones, guardians**

A well-mapped person's adverse situation and needs are essential. In many cases, the insight of the loved ones, the guardian, who can be a significant supporter but also an opponent of the desired change, enters into the solution of the situation.

There are relatives and guardians who accompany the person in the change, are interested in the person's possibilities to live differently and participate in joint meetings with the person, visit new places of living together, participate in the person's transition and support the person.

However, the guardian does not always act in the person's best interests and in accordance with the person's abilities and needs. And it happens that he blocks the change, manipulates the person. Prevention is the involvement of loved ones and caregivers in assessing the person's needs, communicating with them. This is not always successful. It is useful to find out the reason for the carer's attitude and service providers already have options to try to change the attitude (often this is a concern stemming from ignorance of the form of support, conditions, fear for the loved one, but sometimes also disinterest and fear of having to do what the service has done for them so far). If they act fundamentally to the person's detriment, it is possible to petition the guardianship court for a change of guardian or for a decision on the matter. For loved ones who are not guardians, the way is to explain and make the person themselves more competent so that they can set more boundaries and in their decision.

- The output should also determine whether people who have been through the changes - the bearers of the experience - are available/ready for involvement, transfer of experience to others in the country. From among former users of institutional services, from providers - management and staff, people around the person - close public, regional politicians supporting change, etc.

There are to varying degrees people in all of the above roles who can and are willing to share their experience.

Elaborated by: Šárka Hlisnikovská, Daniel Rychlik