

# From institutions to community living: drivers and barriers of deinstitutionalisation

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## INTRODUCTION

Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) sets out the right of all persons with disabilities to live independently and be included in the community. Although the CRPD does not specifically mention deinstitutionalisation (DI) or address the transition process from institutional to community-based support, the Committee on the rights of persons with disabilities (CRPD Committee) has underlined that it is an essential component of fulfilling Article 19.

Achieving deinstitutionalisation is not limited to phasing out certain living arrangements. It entails a profound shift from environments characterised by routine and an ‘institutional culture’, to support in the community where persons with disabilities exercise choice and control over their lives. Realising the right to live independently for persons with disabilities therefore stretches beyond closing institutions and requires development of a “range of services in the community [...], which would prevent the need for institutional care”.<sup>1</sup>

### FRA’s project on the right of persons with disabilities to live independently and be included in the community

To explore how the right to independent living is being fulfilled in the EU, the European Union Agency for Fundamental Rights (FRA) launched a multi-annual research project in 2014. The project incorporates three interrelated activities:

- Mapping types of institutional and community-based services (CBSs) for persons with disabilities in the 28 EU Member States.<sup>2</sup>
- Developing and applying human rights indicators to help assess progress in fulfilling Article 19 of the CRPD.<sup>3</sup>
- Conducting fieldwork research in five EU Member States – Bulgaria, Finland, Ireland, Italy and Slovakia – to better understand the drivers and barriers of deinstitutionalisation.

#### **From institutions to community living – commitments, funding and outcomes for people with disabilities**

In 2017, FRA published three reports exploring different aspects of the move from institutions towards independent living for persons with disabilities:

- [Part I: commitments and structures](#) highlights the obligations the EU and its Member States have committed to fulfil.
- [Part II: funding and budgeting](#) looks at how funding and budgeting structures can work to turn these commitments into reality.
- [Part III: outcomes for persons with disabilities](#) focuses on the independence and inclusion persons with disabilities experience in their daily lives.

<sup>1</sup> European Expert Group on the Transition from Institutional to Community-based Care (2012), [Common European Guidelines on the Transition from Institutional to Community-based Care](#) Common European Guidelines on the Transition from Institutional to Community-based Care, p. 27.

<sup>2</sup> FRA (2017), [Summary overview of types and characteristics of institutional and community-based services for people with disabilities](#).

<sup>3</sup> Indicators are available at: <http://fra.europa.eu/en/project/2014/rights-persons-disabilities-right-independent-living/indicators>. The indicators are based on the human rights model developed by the Office of the United Nations High Commissioner for Human Rights (OHCHR). See: UN, OHCHR (2012), [Report on Human rights indicators: A Guide to Measurement and Implementation](#), HR/PUB/12/5. [Report on Human rights indicators: A Guide to Measurement and Implementation](#), HR/PUB/12/5.

The series complements the Agency's [human rights indicators on Article 19 of the CRPD](#).

Other relevant reports previously published by FRA include:

- [Choice and control: the right to independent living](#)
- [Involuntary placement and involuntary treatment of persons with mental health problems](#)

## Reality check? Local-level research on drivers and barriers of deinstitutionalisation

FRA's fieldwork aimed to give actors involved in the deinstitutionalisation process the opportunity to share their knowledge, experiences and perceptions of what drives the process forward, and the barriers that hold it back. It focused in particular on implementation of deinstitutionalisation at the local level, an area little covered by previous research.

The fieldwork was conducted by FRA's in-country research network, FRANET,<sup>4</sup> in five EU Member States that are at different stages of the deinstitutionalisation process. It was divided into two parts:

- In 2016, interviews and focus groups were conducted in each Member State with various stakeholders from the national and local level (municipalities or cities). The findings led to the identification of one case study locality in each Member State.
- In the first half of 2017, interviews and focus groups took place with a range of stakeholders in the selected case study locality.

This report incorporates findings from both parts of the fieldwork. More information on the research methodology is available in the Annex and the main report presenting the results of the research.<sup>5</sup>

### Why this report?

This report presents the findings of FRA's fieldwork research in Slovakia. Separate national reports capture the results from the four other fieldwork countries.<sup>6</sup>

The report starts by summarising the national context of deinstitutionalisation, including the legal and policy framework and funding, as well as how individuals involved in the deinstitutionalisation process understand some of the key terms and concepts. The rest of the report is structured according to five features emerging from the research as being essential for the deinstitutionalisation process (see table 1). Firstly, the report presents the drivers and barriers of the deinstitutionalisation process in Slovakia, as experienced by participants in the research. It then looks at what participants believe is needed to make deinstitutionalisation a reality.

Within the research, the DI process was explored in depth in a selected locality where the DI process has already started. The selected locality represents to a great extent other localities in Slovakia where the DI process is taking place. The selected locality is a smaller town in a less developed region with a higher unemployment rate. As in many other

<sup>4</sup> See: <http://fra.europa.eu/en/research/franet>.

<sup>5</sup> FRA (2018), *From institutions to community living for persons with disabilities: perspectives from the ground*, Luxembourg, Publications Office.

<sup>6</sup> The national case study reports are available at: <https://fra.europa.eu/en/country-data/2018/right-independent-living-case-studies>.

localities, the situation of an institution in DI is complicated by the fact that the community-based services are almost completely lacking there. However, the institution managed to proceed with the DI process thanks to participation in the so-called National DI Project and good cooperation with the institution's administrator – the respective self-governing region.

A comparative report bringing together the research findings from the five fieldwork countries was published in December 2018.<sup>7</sup>

**Table 1: Key features of a successful deinstitutionalisation process**

1.	Commitment to deinstitutionalisation
2.	Availability of guidance to support the deinstitutionalisation process
3.	Active cooperation between the people involved in the deinstitutionalisation process
4.	A change in attitudes towards persons with disabilities
5.	Practical organisation of the deinstitutionalisation process

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<sup>7</sup> FRA (2018), [\*From institutions to community living for persons with disabilities: perspectives from the ground\*](#), Luxembourg, Publications Office.

## 1. CONTEXT OF DEINSTITUTIONALISATION

### 1.1 Legal and policy framework for deinstitutionalisation

#### 1.1.1 National legal and policy framework for deinstitutionalisation

Many participants in the research across all groups agreed that the policy framework on deinstitutionalisation (DI) developed on the national level is adequate. Among the range of documents referred to by participants, and listed below, the *Strategy for Deinstitutionalisation of the System of Social Services and Substitute Care* was perceived as crucial. Its importance, many noted, lays in the fact that it is not simply a document drafted by the Ministry of Labour, Social Affairs and Family, but it was adopted by the Government. The *National Action Plans for Transition from Institutional to Community-based Care* defines the deinstitutionalisation process in concrete activities and steps to be taken within respective time period.

Deinstitutionalisation in Slovakia is guided by a number of policy documents:

- *National Priorities for the Development of Social Services for 2015 – 2020*<sup>8</sup> – DI is among its top priorities, this policy document spells out development of social services on the community level and gradual replacement of institutions with community-based social services.
- *Strategy for Deinstitutionalisation of the System of Social Services and Substitute Care in the Slovak Republic*<sup>9</sup> – is a basic conceptual document for the process of DI providing basic terms and definitions, stating priorities and activities that need to be taken within the DI process.
- *National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for 2012 – 2015*<sup>10</sup> – the document elaborates on deinstitutionalisation providing more details like managing, financing and monitoring of the process, states also concrete activities for the respective time period.
- *National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for 2016 – 2020*<sup>11</sup> – plans measures and activities in accordance with the DI process and also implementation of the so-called national projects of DI funded by ESIF.

As for the legal framework, research participants referred mainly to the following acts:

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<sup>8</sup> Slovakia, Ministry of Labour, Social Affairs and Family of the Slovak Republic (*Ministerstvo práce, sociálnych vecí a rodiny Slovenskej republiky*) (2014), *National Priorities for the Development of Social Services for 2015-2020* ([Národné priority rozvoja sociálnych služieb na roky 2015-2020](#)).

<sup>9</sup> Slovakia, Ministry of Labour, Social Affairs and Family of the Slovak Republic (*Ministerstvo práce, sociálnych vecí a rodiny Slovenskej republiky*) (2011), [Stratégia deinštitucionalizácie systému sociálnych služieb a náhradnej starostlivosti v Slovenskej republike](#).

<sup>10</sup> Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny*) (2011), [National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for the Period of 2012-2015](#).

<sup>11</sup> Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny*) (2016) [National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for the Period of 2016-2020](#).

- Act No. 448/2008 Coll. on Social Services as amended<sup>12</sup> – stipulates rules for the entire area of provision of social services. The act has been amended several times in recent years to support the DI process.
- Act No. 40/1964 Coll. Civil Code as amended<sup>13</sup> and Act No. 99/1963 Civil Procedural Code<sup>14</sup> – besides many other areas, these acts regulate the process of deprivation of legal capacity and the procedure of its restoration in cases a person has been deprived of his/her legal capacity. Later in 2016, amendments to the Rules of Civil Non-Contentious Litigation<sup>15</sup> (that replaced the Civil Procedural Code) provided stronger safeguards and abolished full deprivation of legal capacity (plenary guardianship), but still allow for partial guardianship.
- Act No. 311/2001 Coll. Labour Code<sup>16</sup> and Act No. 5/2004 Coll. on Employment Services<sup>17</sup> are key among the employment legislation with regard to people with disabilities.

There is an overall agreement among research participants that if we speak about weaknesses of the legislation and of the policy framework adopted on the national level, the problem lies predominantly in its practical implementation (see Chapter 3 for more details). Another problem, participants highlighted, is the lack of measurable goals in national policy preventing effective evaluation of the progress.

### 1.1.2 Local legal and policy framework for deinstitutionalisation

The process of deinstitutionalisation in Slovakia is highly decentralised and is mainly in the hands of actors on the regional and local level, which are independent of central authorities. Authorities and actors in the higher territorial units (self-governing regions), municipalities and institutions (social services providers) are not directly subordinated to the central national authority, which is the Ministry of Labour, Social Affairs and Family, or any other national authority. Self-governing regions and municipalities elaborate their own policy documents on the development of social services, reflecting principles and policies outlined in the national policy framework.

*“The area of social services as such is decentralised to the self-governance level. So, the exact allocation of available funds to concrete projects as well as their volume is determined by particular self-governments, i.e. either higher territorial units or municipalities. In essence, higher territorial units elaborate strategies of developing social services on their respective territories; within the framework of these strategies, they also outline the basic ways of pursuing, say, the national priorities of developing social services.” (National policymaker)*

For the time being, not all self-governing regions have placed deinstitutionalisation as a priority in regional policy documents on development of social services. The self-governing region that is the founder of the institution in the case study locality has incorporated deinstitutionalisation into its policy documents. Some participants attributed this fact as

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<sup>12</sup>Slovakia, Act no. 448/2008 Coll. on Social Services as amended (*Zákon č. 448/2008 Z.z. o sociálnych službách v znení neskorších predpisov*), 20 November 2011

<sup>13</sup>Slovakia, Act no. 40/1964 Coll. Civil Code as amended (*Zákon č. 40/1964 Z.z. občiansky zákonník v znení neskorších predpisov*), 5 March 1964.

<sup>14</sup>Slovakia, Act no. 99/1963 Coll. Civil Procedural Code as amended (*Zákon č. 99/1963 Z.z. občianskysúdny poriadok v znení neskorších predpisov*)

<sup>15</sup> Slovakia, Act No. 161/2015 Coll. Rules of Civil Non-contentious Litigation (*Zákon č. 161/2015 Z.z. Civilný mimosporový poriadok*), Art. 231-251.

<sup>16</sup> Slovakia, Act no. 311/2001 Coll. Labour Code as amended (*Zákon č. 311/2001 Z.z. zákonník práce zákonník práce v znení neskorších predpisov*), 8 August 2001.

<sup>17</sup> Act no. 5/2004 Coll. on Employment Services as amended (*Zákon č. 5/2004 Z.z. o službách zamestnanosti o službách zamestnanosti v znení neskorších predpisov*), 13 January 2004.

facilitating regional authorities in securing additional funding by the region's budget for DI after the national project was over. Overall, however, participants on the local level – policymakers, representatives of institutions and community-based services (CBSs) – did not refer to the policy framework, regardless if national, regional or local as a key factor influencing the DI process.

At the local level, the municipal office in the case study locality also drafted a policy document pertaining to social services. People with disabilities were also actively involved as members of the working group created as a platform for elaboration of the document. The document maps the situation and the support needs of the town's population, town's resources and the capacity of existing social service providers. It further plans municipal activities for the upcoming time period. The situation in the case study locality clearly shows that policy documents of all levels form the necessary framework for the steps to be taken towards DI but are not a sufficient precondition. Participants stressed that national and local policy documents need to be accompanied by concrete measures adopted by the respective authorities. Otherwise the commitment to DI will remain only a formality.

#### **PROMISING PRACTICE**

##### **Evidence-based planning and wide participation**

Evidence-based policy making ensured through the participation of relevant stakeholders in the drafting of the local community plan in the case study locality was singled by participants in the case study locality as a good practice. The working group set for this purpose was coordinated by the director of Social Services Home and brought together relevant local actors including politicians, social, healthcare and educational committees of the municipal office; social workers; teachers; and representatives of people with disabilities.

In addition, the plan was developed drawing on sociological and demographic evidence gathered through research on the support needs and challenges users face in accessing social services in the locality.

The survey identified a need of several social services lacking in the case study locality that would improve the quality of life of different groups, such as day care and social counselling. The research also revealed preference of social services provided in the home environment to such provided in institutions.

Based on the results of the survey and a SWOT analysis (Strengths, Weaknesses Opportunities, Threats), the main aim of the community plan is to improve the quality of life of people with disabilities by securing social services, barrier-free environment, creating opportunities to maintain relations with other people from the locality.

## **1.2 Organisation of deinstitutionalisation**

The Ministry of Labour, Social Affairs and Family is the key central state authority for the DI process. The Ministry drafts policy documents and legislation related to the provision of social services, which are of key importance for the transition from institutional to community-based support. The Ministry also prepares conditions and implements various projects funded by EU funds. With respect to the DI process, the Ministry implemented



the National DI Project (2013 – 2015)<sup>18</sup> within which the Ministry intended to test the possibilities of transformation of institutional to CBSs on the sample of 10 institutions (three in Bratislava region, seven in other regions). Within the National DI Project, the Ministry also created a committee of experts for deinstitutionalisation that has the competence to monitor the DI process and evaluate the progress made. When asked about this first National DI Project, participants on the regional/local level associated it with many implementation problems and raised doubt about the quality of the project interventions (see Chapter 3).

Higher territorial units (self-governing regions) have many competences with regard to provision of social services. They draft their own policy documents related to the provision of social services within their territory. They establish social service providers and register those that are founded by actors other than regional authorities. Self-governing regions also allocate funds to individual social service providers. They are also expected to follow the policy principles stipulated by central state authorities (mainly by the Ministry of Labour, Social Affairs and Family), even if they are independent from the central state authorities to a large extent. As administrators of institutions, the respective self-governing regions were also involved in National DI project, however, their representatives evaluated that they were very often omitted from the project communication.

Municipalities are legally obliged to establish and provide certain types of social services, mainly field and outpatient social services. They are also responsible for the planning and respective funding of services in their locality. With regard to the DI process, the representatives of municipalities believe that they do not have any specific responsibilities, since until now the DI process has been tied rather to particular institutions (and their administrators) than to individual localities/communities. However, the representatives of institutions who took part in the National DI Project encountered many problems like opposition of local communities and lack of CBSs that could be effectively solved in cooperation with municipalities.

Social service providers are obliged to fulfil conditions stated by the legislation and respect the rules adopted by their founders. They can be founded by self-governing regions, municipalities or other legal entities such as NGOs or for-profit companies.

Division of competences in provision of social services is perceived by research participants as an obstacle for the DI process, since competences of self-governing regions (as well as municipalities) to decide on their priorities in the area of social services are rather broad. So, for instance, if they decide they are not going to create favourable conditions for the DI process, the national (state) authority cannot force them to do so.

*“Another thing is that regional self-governments are not explicitly expected to go for [the DI process]; in other words, if all regional self-governments in Slovakia said they refused to tackle it, nothing would happen. The money will simply not be spent on [deinstitutionalisation]; they will be drawn and spent on other things because the programme is rather broad.” (Regional policymaker)*

Another problem mentioned by research participants is the fact that self-governing regions are not directly subordinated to the Ministry of Labour, Social Affairs and Family, so the Ministry is not able to intervene directly into the situation of a particular institution.

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<sup>18</sup>Slovakia, Implementation Agency of the Ministry of Labour, Social Affairs and Family of the Slovak Republic, [Národný projekt Podpora deinštitucionalizácie a transformácie systému sociálnych služieb](#).

*"It is [self-governing regions] who have to implement [the process]; the Ministry can hardly do anything, as it does not administer anything. [The Ministry] cannot change anything, since it doesn't have anything, it doesn't manage anything. The Ministry does not operate a single facility it could change; that's what I meant to say. Therefore, it is up to administrators to make the changes."* (National policymaker)

Although not being actively involved in implementation of the DI process, the Commissioner for Persons with Disabilities believes that the process has been in such a progress so far that it cannot be halted. In her view, the demand for DI has increased since policy documents adopted to date have raised expectations for change in service providers, NGOs and people with disabilities themselves.

### 1.3 Funding for the deinstitutionalisation process

In Slovakia, the DI process is mostly funded by the European Structural and Investment Funds, mainly the European Social Fund (ESF) for so called 'soft measures' and the European Regional Development Fund (ERDF) for construction related measures. The DI process started by involving 10 institutions in the so-called National DI Project<sup>19</sup> funded by ESF and implemented by the Implementation Agency of the Ministry of Labour, Social Affairs and Family. Within this project, several manuals for the transformation of institutions were elaborated, staff were trained in new working methods and transformation plans for the involved institutions were drafted.

Originally it was planned that ERDF funds will be used complementary to the resources from ESF and would serve for purchasing real estate property needed for relocation of institutions' clients into supported/independent living arrangements. However, this plan has not been accomplished for any of the institutions involved in the National DI Project.<sup>20</sup> Several obstacles to drawing of ERDF were reported in this research. In addition to suspicion of corruption, participants referred to hurdles related to bureaucracy of the public procurement system and re-direction of available resources to other priorities.

Within the course of 2017, the Ministry of Agriculture and Rural Development made the funds from ERDF accessible and opened a call within which existing institutions could apply for funds needed for physical transformation and creation of new types of social services. However, the problem of coordination of drawing from the funds, both from ESF and ERDF, still persisted at that time since the funding of soft measures (preparation of transformation plans, training of staff and clients of institutions) had been delayed compared to the funding of physical transformation of existing institutions.

There are also smaller resources available for the DI process from non-governmental organisations such as SOCIA Foundation that continuously supports the DI process and cooperates with several institutions that undergo (or plan to undergo) DI.<sup>21</sup>

As the findings show, additional funds were needed in the case study locality to proceed with the DI process. After the National DI Project finished at the end of 2015, the self-governing region decided to allocate extra funds for further steps to be taken within the DI process. The region decided to finance the increased costs of the higher number of staff

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<sup>19</sup>Ibid.

<sup>20</sup> Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny*) (2016) [National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for the Period of 2016-2020](#), p. 11.

<sup>21</sup>SOCIA Foundation, 'Podpora deinstytucionalizácie', see: [www.socia.sk/nase-aktivity/aktualne-aktivity/z-domova-domov/](http://www.socia.sk/nase-aktivity/aktualne-aktivity/z-domova-domov/) and [www.zdomovadomov.sk/](http://www.zdomovadomov.sk/).

within the institution and also, two flats in the town were bought and renovated for starting a supported living unit. Nowadays, the institution operates within the original building and provides also services within the new supported living unit where six clients have been relocated. The number of institution's staff is almost twice as high as required by law. According to the representative of the region, the number of staff is much higher compared to other institutions within their competence, which means that the region must also allocate much more finances for operation of this institution than for other institutions they administer. Recently, there have been further steps taken within the DI process. The institution plans to establish more supported living units/flats by using ERDF funds, and the town administration has created a few additional social services in the community.

According to participants of the regional/local level, funding of the DI process in Slovakia does not take into account various categories of costs increasing once the DI process is initiated. ESF funds are available only for the phase of preparation – training of staff and clients and elaboration of transformation plans. Funds needed for the physical relocation of clients are available from ERDF, however, actors of all levels reported that the problem lies predominantly in lack of coordination of these two funds as each of them falls under the competence of different ministry. Additional funds that would allow to cover the operational costs (mainly higher number of staff) are not available at all. Thus, in a situation of lack of funds for the DI process, a great deal of responsibility for the DI process lies on the shoulders of self-governing regions that are burdened with high expenditures of social services provision anyway. One of the participants explained the process from a self-governing region perspective:

*“There are absolutely no [budgetary] funds earmarked to [finance provision of social services] during the so-called transitional period, which may take years; it is a general understanding that everybody will pay their own bills. But it is not that simple because, for instance, we receive no money; if we receive any, it is channelled from structural funds. We can only ask for funds to cover investment or capital expenditures, which means [no money for] operational costs but operational costs are basically equal to investment costs. We don't receive financial support from the state budget that would help us cope with the process.”* (Regional policymaker)

#### 1.4 The status of deinstitutionalisation

The DI process in Slovakia started with the adoption of the *Strategy of Deinstitutionalisation of the System of Social Services and Substitute Care* (2011)<sup>22</sup>, followed by a dedicated *National Action Plan*<sup>23</sup> and making EU funds for the process accessible. However, it should be noted that before these steps were taken by national authorities at the national level, the idea of DI process had been promoted by several NGOs and experts active in this field. Thus, the initiative of national authorities partly stemmed from and drew on the expertise of the non-governmental sector.<sup>24</sup>

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<sup>22</sup>Slovakia, Ministry of Labour, Social Affairs and Family of the Slovak Republic (*Ministerstvo práce, sociálnych vecí a rodiny Slovenskej republiky*) (2011), [Stratégia deinštitucionalizácie systému sociálnych služieb a náhradnej starostlivosti v Slovenskej republike](#).

<sup>23</sup> Slovakia, Ministry of Labour, Social Affairs and Family (*Ministerstvo práce, sociálnych vecí a rodiny*) (2011), [National Action Plan for Transition from Institutional to Community-based Care in the Social Services System for the Period 2012-2015](#).

<sup>24</sup> For more information on development in social services from human rights perspective please see: Cangár, M. (2017), [Prechod z inštitucionálnej na komunitnú starostlivosť v Slovenskej republike](#), Bratislava, SOCIA.

The mentioned legislative and policy commitments and activities towards DI were taken up by national authorities following the publication of a report in 2009 by the EU Commissioner for Economic and Social Affairs, Vladimír Špidla, on the use of EU funds to maintain large institutions.<sup>25</sup> This led to the European Commission freezing the use of European Structural and Investment Funds (ESIF) for institutions in Slovakia, and prompted the process.

A pilot National DI Project<sup>26</sup> covering ten institutions was implemented between 2013 and 2015. In spite of reported shortcomings, the project initiated the DI process in Slovakia. Research participants of the regional/local level commented on the insufficient coordination by national authorities of the process; and bureaucratic burden connected with the project's administration, which resulted in hasty and uncoordinated implementation of the activities.

Even though relevant laws do not mention specifically the term deinstitutionalisation, national policymakers who participated in this research, referred more often than other participants, to the existence of a governmental strategy as a positive driver of the DI process. They considered that through a strategy the government has expressed its commitment to the process. Participants also referred to a few legal changes, which facilitate the DI process (amendment of Act No. 48/2008 Coll. on Social Services and Act No. 40/1964 Coll. Civil Code). For instance, a maximum number of places in an institution was introduced to prevent the formation of large-scale institutions; new form of social services – supported living – was incorporated into the law which is perceived as a progressive form of social service that allows a high degree of independence of clients, etc. The Act also introduced a system for quality assessment social services; however, the implementation of the evaluation procedure has been postponed for several times already.

A significant amendment of legislation abolishing plenary guardianship was adopted in 2016. Amendments to the Rules of Civil Non-Contentious Litigation<sup>27</sup> introduced stronger safeguards, abolished full deprivation of legal capacity (plenary guardianship), but still allow for partial guardianship. It is now also possible for people (including persons with disabilities, their guardians, families or close persons) to challenge guardianship decisions and request annulment of guardianship measures. So far, however, the process proves to be lengthy and difficult, if not impossible.

Overall, besides legal and policy developments in the last years, representatives of NGOs and social services providers argued that even if policy documents are well written, they lack implementation and fail to establish concrete actions to be taken within the forthcoming DI process. Another concern raised was that there were no financial schemas attached to these documents and existing community-based services are not ensured financial stability. The monitoring and supervision of the DI process was reported as insufficient. The evaluation of quality of social services that should have been introduced by the amendment of the Social Services Act has been postponed for several times already. According to some participants, existing institutions will not meet the quality criteria once the evaluation procedure is put into practice.

In September 2016, another National Action Plan was adopted that envisages the continuation of the DI process by involving more institutions compared to the first National

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<sup>25</sup>Špidla, V. (2009), [Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care](#), Brussels, European Commission.

<sup>26</sup>Slovakia, Implementation Agency of the Ministry of Labour, Social Affairs and Family of the Slovak Republic, [Národný projekt Podpora deinštitucionalizácie a transformácie systému sociálnych služieb](#).

<sup>27</sup> Slovakia, Act No. 161/2015 Coll. Rules of Civil Non-contentious Litigation ([Zákon č. 161/2015 Z.z. Civilný mimosporový poriadok](#)), Art. 231-251.

DI Project. The institutions involved in the new DI project will establish transformation teams and draft transformation plans based on the experience gained during the first National DI Project. However, by the end of 2017 (the time of drafting of this report) the new National DI Project has not started. Participants in the research raised concern about the continuation of the National DI Project. In their view, there is no clear structure, no funding allocated yet, lack of communication and information to service providers and organisations. Alarming also, the issue of who will lead the project is yet unclear, as three expert NGOs working in the area of deinstitutionalisation were asked for co-financing, which would be impossible. Several open letters<sup>28</sup> have been sent to responsible political actors on these issues, with no reply at the time of writing has been no reply so far.

The Committee on Petitions of the European Parliament (PETI) paid a visit to Slovakia in September 2016 following the petition by the Mental Health Initiative of the Open Society Foundations. The petition concerned the investment of the EU funds into residential institutions for people with disabilities instead of funding the DI process. After consulting relevant NGOs and the Slovak authorities as well as conducting visits to different types of facilities, PETI Committee proposed several recommendations. Those include: speeding of the transition process, enforceability of independent living, involvement of people with disabilities in the DI process and efficient monitoring of the process.<sup>29</sup>

Looking specifically at the status of deinstitutionalisation in the case study locality, except for the Slatinka Home for Social Services, the institution in the research locality is further along in the DI process compared to other institutions/localities in Slovakia. Evidence shows that this is because the administrator of the institution decided to fund additional steps in the DI process from its own budget. Nowadays, the institution runs one supported living flat in the town where a small group of clients was relocated in the first half of 2016. The rest of the clients still live in the original building. However, the institution continues to implement its transformation plan. It cooperates closely with the self-governing region in planning the relocation to the community of more clients still living in the institution and intends to use ESIF funds to enable further steps once the funds will be available.

## 2. UNDERSTANDING OF DEINSTITUTIONALISATION AND INDEPENDENT LIVING

### 2.1 Key terms and concepts

- **Understanding of deinstitutionalisation and independent living**

In Slovakia, the DI process is only in its beginnings, which might also have an impact on the stakeholders' understanding of the term of deinstitutionalisation – both on the national and local level. In general, the majority of stakeholders perceive deinstitutionalisation as a good direction in the provision of services for people with disabilities. However, understanding of this process and its purpose varies. There is no clear distinction among what was reported by different groups of stakeholders or levels of governance (national, regional, local). In many cases, representatives of the same type of institution or administrative unit had a completely different understanding of DI – based on their personal beliefs and informed by their own experience.

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<sup>28</sup>TASR, [Organizácie: Proces transformácie sociálnych služieb zastal](#), 30 May 2017.

<sup>29</sup>Committee on Petitions of the European Parliament (2016), [Mission Report and Recommendations following the Fact-finding visit to Slovakia of 22-23 September 2016](#), 29 November 2016.

Generally, participants, especially representatives of municipal or regional offices and service providers, view the DI process as a break-down of large institutions into smaller units such as supported living flats or independent living arrangements of groups of people with milder forms and degrees of disabilities. Transformation of large institutions is often understood as physical transformation – rebuilding of current institutions and providing a better quality of life for people with disabilities.

However, other actors – such as disabled persons’ organisations (DPOs), some of the service providers and national-level stakeholders – see DI as a process of changing the philosophy of services provided to people with disabilities. They spoke about ‘humanisation of services’, human rights based approach and individual assessment of people with disabilities’ needs as core elements of the DI process.

*“Ehm, the whole time I am thinking about how to describe DI with one word and I guess it would a revolution. [...] Revolution towards humanity.” (Employee of a social service)*

According to a representative of an NGO, instead of deinstitutionalisation the term ‘humanisation’ of social services is often used. He stressed that within such ‘humanisation’ process the institutional practices are only softened and do not lead to real change in philosophy of provision of social services and true independent living outcomes.

Stakeholders on the local level who have direct experiences with DI spoke about the process as allowing a more personalised approach towards clients, a more focused therapy and individual activities for clients. As a result, clients are more self-sufficient and more involved in everyday activities.

However, with the exception of one research participant who spoke about DI process as resulting in living in a home environment with one’s relatives, the majority of research participants were convinced that some form of institutional care (supported living, smaller institutions, groups of people with disabilities living together) is necessary for the DI process to be efficient.

Clients themselves who are in the process of DI perceive that they have more control over their lives with more personal space and autonomy, even if they live in supported living arrangements under staff supervision.

- **Institution and community-based services and differences among them**

There was a broad consensus among all participants in their understanding of what defines an institutional services compared to such based in the community. All participants in the research – across groups and levels of governance – see great differences between these two types of care provided to people with disabilities. Since services based in the community are not yet sufficiently available throughout Slovakia, stakeholders described rather their theoretical benefits. However, participants from localities where the DI process has already started, could provide evidence on benefits for people with disabilities living in CBSs such as greater visibility in the community and involvement in broader community activities leading to social cohesion.

In general terms, institutions are perceived as very rigid and not flexible environments. Traditionally, institutions for people with disabilities in Slovakia were located in large old buildings, such as old manor houses isolated from the community in remote areas. This acted as key barrier for persons with disabilities to maintain relations with people in the community. Their social life was thus limited to relations with staff.

According to different stakeholders, institutions are ruled by a very strict and rigid regime, which means they are not open for change. The participants spoke about the inability of an institution to respond to individual needs of clients, leading to learned dependency of people with disabilities. Furthermore, they stressed that institutions focus predominately on healthcare.

On the contrary, community-based services are viewed as a more human way of providing services to people with disabilities. CBSs entail more individualised approach based on each client's needs and preferences. Since they are provided on the community level, people with disabilities may receive services that are provided to the general public, not only those related their impairment (such as health, social and mental health services).

*"For me, well for the people, in my opinion, it means an individual approach with respect to the living conditions, so no standardised services in large facilities, but custom-fit living conditions for each individual client, what he/she needs, be it social services or employment or different kinds of support and compensations, so that they can access all of this. So that they would not be in a large facility in which the individuality dissolves."* (Representative of a national human rights body)

Within CBSs, people with disabilities receive only services they really need, which allows them to build self-confidence and prevent learned dependency. The services tend to be more responsive to the individual needs of clients.

*"It is crucial that staff strives to seek individual ways to enable people to make independent decisions about their own lives as much as possible."* (National policymaker)

CBSs employ more human approach while respecting the rights of people with disabilities. CBSs also provide an opportunity to live independently – stressed mainly by people with disabilities availing of such support themselves. What distinguishes community-based services from institutional care is freedom of movement, more control over their lives and choices and more privacy.

Unlike institutional care, community-based services create more room for participation of people with disabilities in the life of community. Therefore, participants view it as important to provide services in the clients' place of residence.

*"For me, when something is community-like and it is to be a community service, it should be done in the community where one lives. And this is the difference. When [DI] takes place outside the place of residence [...] of those people and their family, so it's no longer a community service. For instance, if we take a person from Rača and put him into a facility in Malacky or in Stupava, it's not a community service, even though he/she will have a beautiful house there with a garden and orchard."* (Local politician)

- **Deinstitutionalisation and independent living for persons with different types and degrees of impairment**

On a theoretical level, many actors were convinced that the philosophy of deinstitutionalisation and applying a human rights approach is based on the assumption that DI should include all people with disabilities, regardless of the type and degree of their impairment. Some of the stakeholders, in particular representatives of public

authorities, disabled people's organisations (DPOs) and NGOs think that also people with severe disabilities can live independently in the community.

However, in practice, most respondents, regardless of their profession and active engagement in the DI process, see some limitations for different groups of people with disabilities. Professionals who are already involved in the DI process in particular are convinced that DI is 'not suitable', in other words not possible, for people with more severe types of disabilities. Following views were expressed by respondents.

- **DI is viewed as not suitable for people with severe disabilities and people who are not mobile**

Local level stakeholders and representatives of service providers from the case study locality shared that, in their view, it was not possible to achieve independent living for immobile persons and those with severe disabilities. The scope of support services (health, social, etc.) for them is very broad and thus only institutions can provide adequate services to people with severe disabilities.

In their view, institutions can offer a better quality of life, since they provide health care and social services that could not be provided in the home environment. The quality of health care was understood as much more important than independent living.

*"You certainly cannot speak of any preparation with respect to clients who are immobile and deaf, blind and so on; you can only speak of improving the quality of their lives, which can be attained through good rehabilitation."* (Manager of a social service)

- **DI is viewed as not suitable for people with psychosocial disability**

Another group broadly perceived by research participants as not suitable for living independently in the community are those with psychosocial disabilities. Concerns, mainly raised by service providers, include: fear of aggressive behaviour; posing danger to themselves and others; increased stigmatisation and fear of the people in the community who would be reluctant to accept people with psychosocial disabilities.

- **DI is viewed as not suitable for people who have lived in an institution for most of their lives**

Older people and those living in an institution for most of their lives are another group which was viewed by participants as not suitable. Participants spoke about increased "learned dependency" which would make the process of transition more difficult.

## 2.2 Impact of deinstitutionalisation

DI in Slovakia is just starting and has not been accomplished yet. However, stakeholders commented on various outcomes already observed at these early stages.

Representatives from municipalities (regional and local) spoke about many challenges, stemming from the lack of information campaign (due to the lack of funding), which led to a low public awareness on this topic. People's negative attitudes have an impact on the implementation of DI.

*"Then, when we singled out the one [facility] that seemed to be the best in terms of the clients' lowest average age, the locals stood up against the idea. It was in*



*[location]. [The locals] even appealed to their deputy in the regional parliament and we had to write back to them, but it was rejected. The parents opposed it. I don't know whether it was a communication failure [between the staff, the regional self-government and the parents]; all I know they were opposed to it from the very outset. [The project] failed eventually. [...] We had truly serious problems in the beginning; our entire department was involved in it.*" (Regional policymaker)

Representatives of service providers also confirmed that negative attitudes and misunderstanding of the purpose and philosophy of DI had a negative impact on their work. However, people with disabilities are becoming more "visible" and involved in different activities organised in the community. Thus, the attitudes are changing positively as a consequence of the DI process.

*"The fact that they are outside, that they can [leave the institution] and pursue a more active form of existence. If I am to return [to the original question], I think it is not as necessary [for their sake] –of course, it is also good for them as they have a chance for personal improvement, but I believe it is rather about the common good, about making people come together. I mean, really, we live in a small town and we know how these things are – sometimes we envy each other even a nose between the eyes. Let me put it straight because I don't have a problem with that: this is often the case here. I believe the more independent and more visible they become, the more other people are forced to perceive the new situation that has come into being."* (Member of the local community)

Another positive impact of the DI process, reflected on by research participants, was the opportunity for different local-level actors (such as service providers and municipal officers) to develop skills in providing community-based services and to intensify cooperation among different actors. For some of them, participation in DI also helped them learn good practices from abroad.

On the personal level, service providers learned to employ individualised approach to clients.

The non-existence of community-based services negatively influenced the work of individual service providers. On the one hand, institutions are broken down to either smaller units or survive only as administrative centres. On the other hand, they need to create community-based services themselves, as neither the state nor the municipality authorities took over this task.

*"[...] we, too, had to cut one facility down at the moment – we simply have to create supporting services, because there is no special agency for supported employment, there are no rehabilitation centres, sheltered workshops and these are simply subjects we need out in the field. And we need them to live and be active."* (Manager of a social service)

Even though the DI process has an impact on the work of service providers and other stakeholders, DI affects most significantly the lives of people with disabilities themselves. According to the employees of the institution in the case study locality, their lives improved considerably.

*"That's right, because they simply found out that their life has become more similar to ours, you see? I mean, they see us coming to work and then leaving to return to our families. Likewise, when [these clients] who live in the apartment in town, they say, like, we must hit the sack because we have to go to racket in the morning.*

*So, they see that their life has grown a bit like ours, as my colleague has said, and that really makes them happier.” (Employee of a social service)*

All people with disabilities participating in the research assessed the DI process positively. According to them, DI had a strong impact on their lives. The more independently they live outside the institution, the better their life is. Positive impacts can be summarised as: a possibility to make their own decisions and to have more control, higher self-esteem and self-sufficiency, better interactions with others in the community. The positive impact of DI was also described in terms of greater visibility of people with disabilities, maintaining contacts with people from the community and participation in various cultural activities organised by the community or the city hall.

### **3. ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS**

ESSENTIAL FEATURES	KEY DRIVERS	KEY BARRIERS
<b>3.1 Commitment to DI</b>	<p>3.1.1 International commitment of Slovakia to fulfil the rights of people with disabilities by implementing the DI process</p> <p>3.1.2 National policy documents (strategies, action plans) and respective amendment of legislation for supporting the di process</p> <p>3.1.3 Commitment of the self-governing regions to DI</p> <p>3.1.4 Commitment of managers of institutions to DI</p>	<p>3.1.5 Lack of clear commitment and failure to implement the DI process on the part of the state</p> <p>3.1.6 Lack of committed and trained employees</p> <p>3.1.7 Adversity to EU Funds, corruption and "grey politics"</p>
<b>3.2 Availability of guidance to support the DI process</b>	<p>3.2.1 Positive examples of DI from abroad</p> <p>3.2.2 Exchange of information among institutions/regional authorities</p> <p>3.2.3 Training workshops and consultations provided during the National DI Project</p>	<p>3.2.4 Lack of information about the DI process and poor guidance</p> <p>3.2.5 Lack of proper and adequate preparation</p> <p>3.2.6 Discontinuity in implementation of National DI Projects</p> <p>3.2.7 Lack of practical information and good practice examples</p>
<b>3.3 Active cooperation between the people involved in the DI process</b>	<p>3.3.1 Cooperation between institutions and their regional administrator</p> <p>3.3.2 Cooperation of other relevant stakeholders on the local level</p> <p>3.3.3 Cooperation of the institutions and NGOs/DPOs</p>	<p>3.3.4 Insufficient communication</p> <p>3.3.5 Lack of active cooperation between national, regional and local level actors</p>
<b>3.4 A change in attitudes towards persons with disabilities</b>	<p>3.4.1 Change in attitudes of the local population</p> <p>3.4.2 Changes in attitudes of the institution's staff towards the DI process</p> <p>3.4.3 Expectations of people with disabilities and their families that the DI process will be put into practice</p>	<p>3.4.4 Employee attitudes</p> <p>3.4.5 Attitudes of communities and families</p> <p>3.4.6 Fear of clients and learned dependence</p>
<b>3.5 Practical organisation of the DI process</b>	<p>3.5.1 Employing new working methods and organisation of work</p> <p>3.5.2 Higher share of professional staff to be able to create the transformation team</p> <p>3.5.3 Funds available to cover the increased costs necessary for the transformation phase</p>	<p>3.5.4 Lack of finances for transformation of institutions and cbss and their sustainability</p> <p>3.5.5 Lack of CBSs and inaccessible general services</p> <p>3.5.6 Lack of opportunities for further integration</p> <p>3.5.7 Deprivation of legal capacity</p> <p>3.5.8 Barriers in legal setting and bureaucratic burden</p>

### 3.1 Commitment to deinstitutionalisation

#### 3.1.1 Driver 1 – International commitment of Slovakia to fulfil the rights of people with disabilities by implementing the DI process

The importance of international commitment was emphasised by many participants in the research, notably those who are the most active and devoted to DI. The human rights perspective anchored in the Convention on the Rights of Persons with Disabilities, ratified by Slovakia in 2010, serves as an important source of personal motivation.

*"So, we are rather speaking of self-governments that understand what it means [...] the process of transforming social services, deinstitutionalisation process, but first and foremost understand that the rights of persons with disabilities are very important. [I would say] it is the duty of a self-government to fulfil the Convention on the Rights of Persons with Disabilities and its Optional Protocol. [...] they don't perceive it as something they must do, but as something they want to do, because it is their people they do it for." (Regional policymaker)*

#### 3.1.2 Driver 2 – National policy documents (strategies, action plans) and respective amendments of legislation for supporting the DI process

National-level authorities pointed to the policy framework, in particular the Strategy for Deinstitutionalisation adopted by the government as a driver for the transition process (for more details see chapter 1). In their view, apart from the relevant policy documents amendments of existing legislation also support the DI process, as they prohibited building new large-scale institutions and gave community-based services priority over social services provided in institutions.

#### 3.1.3 Driver 3 – Commitment of self-governing regions to DI

Since the provision of social services is decentralised in Slovakia, self-governing regions play an important role in organising social services. The research findings show that not all regions support the DI process equally. There are regions in Slovakia that oppose the process, whereas other regions act actively to push it forward. They did not only address DI into their regional policy documents, but also adopted measures and activities to proceed with the DI process in practice.

Several representatives of institutions and self-governing regions stressed that there are many small steps that can be done without much investment. They say that even if the continuation of National DI Project is uncertain, they can at least take these minor steps like completing the transformation plans, ensuring the exchange of information among institutions and supporting the creation of community-based services.

*"For the time being, self-governments are driven mostly by their own motivation and are able to adopt at least small measures; for instance, we have been developing community care services for six or seven years now." (Regional policymaker)*

#### 3.1.4 Driver 4 – Commitment of managers of institutions to DI

Operating in rather unfavourable conditions towards DI, the commitment of the institution's management showed to be a crucial precondition when implementing the DI

process in Slovakia, since there are many responsibilities that fall concretely on the institution's management.

Beside the communication with the administrators, institutions act towards the other local actors, local authorities and community. Within the institution, the management needs to pursue and motivate their own employees to actively take part in the DI process. The fieldwork research revealed that institutions in the DI process were motivated to start with DI by several factors. Some of them were pushed to the process without having a lot of chance to refuse. Some of the institutions were afraid that they would be somehow penalised for refusing to take part in the project, for instance by reducing the number of staff. Other institutions used the opportunity to improve their working conditions, mainly in terms of renovation of workspaces. Furthermore, motivation and commitment of the institutions involved also stemmed from the fact that they wanted to increase the quality of social services they provide for their clients. They also perceived the DI process as a professional challenge.

#### **PROMISING PRACTICE**

##### **Best practice in DI process in Slovakia – deinstitutionalisation of Slatinka home of social services**

Slatinka home of social services (*Domov sociálnych služieb Slatina – DSS Slatinka*) has been in the process of DI since 2008 and currently has 69 clients, out of which 15 persons with severe disabilities still live in the institution. Other clients have been gradually relocated to the supported-living flats or smaller buildings in the centre of the town. Currently, DSS Slatinka includes more than eight flats for supported living, one building that serves as an institution, day care centre and week centre, and two other premises<sup>30</sup>.

The DI process of Slatinka institution started due to their own commitment to improve the life of their clients. Gradually, they supported their clients in independence and life in the community.

In 2013, they joined the National DI Project, led by the Implementation Agency of the Ministry of Labour, Social Affairs and Family, within which they were supported in form of preparation of leadership and employees.<sup>31</sup> Similar to other institutions involved in the National DI Project, DSS Slatinka never got to the next part of the process – the physical transformation of the home. However, in their case this was caused due to halting the funds by the regional governor.

Several research participants – representatives of disabled persons' organisations, service providers, policymakers – and those from other institutions undergoing the DI process referred to the process in DSS Slatinka as a promising practice. Few elements were highlighted. Foremost, DSS Slatinka achieved measurable outcomes, despite the fact that they went through the DI process on their own costs. The process was financed by their own budget received from the self-governing region and the grant money they received for various projects, mainly from the Open Society Fund – the Open Mental

<sup>30</sup>Brichtová, L., Filipová, M., Končeková, D., Kopicová, E., Samová, M. (2015), *Závěrečná hodnotící správa. Národní projekt Podpora deinstitucionalizace a transformace systému sociálních služeb v Slovenské republice*, Bratislava, Implementation Agency of the Ministry of Labour, Social Affairs and Family, p. 128. For other information on the DI process at Slatinka, see: Holúbková, S., and Ďurana, R. (2013), *Odvaha na nové služby*, Bratislava, INESS, p. 28, or SOCIA (2015), *Simple happiness* (film with English subtitles).

<sup>31</sup>Implementation Agency of the Ministry of Labour, Social Affairs and Family, [Základné informácie 'Základné informácie'](#).

Health Initiative. The institution has also a year-long cooperation with the SOCIA Foundation – an NGO, which supports the DI process actively also on the national level. In addition, they successfully moved out most of their clients from the old manor house to several smaller properties around the town.

Another outcome of the DSS Slatinka's transformation process mentioned by one of the research participants is that their clients, previously assessed as highly dependent on care, developed considerably independent living skills after their relocation to the community supported services in Lučenec and now live almost fully independently.

One of the research participants from an NGO mentioned another important success feature: the institution also allowed their clients to actively engage in the promotion of their rights. The DSS Slatinka's clients were present at the hearing of the Slovak Republic before the UN Committee on the Rights of Persons with Disabilities in 2016. During a side event before the Committee, they spoke about the impact the transition process had on their lives and of what all they had gone through.

### 3.1.5 Barrier 1 – Lack of clear commitment and failure to implement the DI process on the part of the state

Almost all participants in this research perceived that DI is not a priority in Slovakia. They spoke of the process as being seen as the “necessary evil” and no one in senior political levels really interested. The main motivation behind the start of the process was the freeze of structural funds by the European Commission in 2010 following Commissioner Vladimír Špidla’s report on the use of EU funds in large institutions with a combined capacity of 3,000 people.<sup>32</sup>

*“I wouldn’t call it [a priority]. The project of deinstitutionalisation obviously lacks political backing.”* (Representative of a non-governmental organisation)

The lack of genuine political commitment – according to research participants – is transposing into poor implementation of the national legal and policy instruments for DI. Even if national strategy documents and action plans and strategies were assessed by various groups of respondents as very good and beneficial for pushing for DI, many stressed that they lack legal enforceability, provision of sanctions when not implemented, clear and strict timeline and adequate allocation of state funding. Overall, participants stressed that DI is well developed on paper, but in reality implemented only formally.

*“Well, on paper, we have gone quite far, because we have the deinstitutionalisation strategy, which is even cited sometimes as an example of good practice, like this is the way to go. We have defined national priorities that stipulate our ambition to support the development of community-based services. We have several legislative signs [of improvement, for instance provisions] that prevent the registration of new homes of social services. Certain capacity limitations, quality criteria and individual planning have been enacted. So yes, we are quite far along the way on paper. However, we are lagging behind terribly in terms of implementation; [we have a long way to go in terms of] changing the system of evaluating dependence, financing social services and introducing active support.”* (Representative of a non-governmental organisation)

These, many assessed, results in a slow DI process, with very few institutions undergoing

<sup>32</sup> Spidla, V. (2009), *Report of the Ad Hoc Expert Group on the Transition from Institutional to Community-based Care*, Brussels, European Commission.

transformation on the regional and local level (as compared to for example the DI of foster care homes). Towns and regions are not forced to implement the strategies and undergo the DI process and can even finance and support adverse activities, such as investing in modernisation of existing institutions instead of community-based services, through the regional and local budget.

### 3.1.6 Barrier 2 - Lack of committed and trained employees

Another challenge identified by participants both at the national, as well as local level, is the lack of trained and committed employees. Several reasons were reported as to why employees, and directors of institution, are sceptic towards the DI process. These are: lack of national campaign that would inform all relevant stakeholders about its benefits, and lack of experience with DI including the shortage of successful case studies.

Another barrier identified in the research relates to the low salaries of staff in social services resulting in a very low number of qualified and trained young employees. In many regions of Slovakia with higher unemployment rate, employees also fear of losing their job or are resistant to changing their work patterns.

As one national-level representative noted, the institutional culture prevailing over many years resulted in employees' learned stereotypes with established working style. These now have to be changed, including shifting understanding towards a rights based approach to disability.

*"Facilities have their own stereotypes, which employees would not like to see changed. It may also turn out to be a problem for them; a status problem that is. The nurses [at the facilities] wear white cloaks and don't understand why they should take them off all of a sudden; [they perceive them as] their protective working clothes."* (National policymaker)

### 3.1.7 Barrier 3 – Adversity to EU Funds, corruption and “grey politics”

The first National DI Project started with 10 institutions and provided employees with soft skills. The following phase was supposed to finance the physical transformation of the institutions into community-based (supported) living. However, due to several reasons, no institution underwent a physical transformation at that time.

One of the reasons, identified by the research participants, relates to specific issues in some self-governing regions – either adverse or hostile reactions, or suggested corruption in the process of public procurement.

For example, the physical transformation of two institutions in the Banská Bystrica region have been directly affected by the adverse activities of the self-government led by a governor with an extreme far-right political affiliation. The governor refused to sign the EU funding for two institutions in the region due to his anti-systemic views on the EU and his contemptible views on people with disabilities.<sup>33</sup>

Suggested corruption and "grey politics" was also reported by several respondents as directly hindering the DI process in Slovakia:

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<sup>33</sup> See for example: SITA (2014), *Kotleba má výhrady k projektu, BBSK môže prísť o eurofondy*, WebNoviny, 10 October 2014.



*"It is such a challenge to do it with those people, you are working with the institution and you motivate clients, clients are ready, you have prepared the employees, and then all of a sudden, somewhere in the background something happens between the self-governing region and the director, and then nothing [...]. I mean so there was this grey politics, which is in fact such a challenge [...]." (National policymaker)*

## 3.2 Availability of guidance to support the deinstitutionalisation process

### 3.2.1 Driver 1 – Positive examples of DI from abroad

Witnessing positive examples of DI from abroad was mentioned by all categories of the research participants as a very important driver of the DI process. Several research participants (representatives of NGOs, institutions, public authorities) had an occasion to visit a variety of transformed institutions and CBSs in the Czech Republic, Norway and other countries. These visits led to gaining practical information and guidance and strengthened their personal motivation.

Participants stressed that it's important that various categories of actors have an opportunity to gain first-hand experience. In case of the case study locality, not only the institution's managers visited locations abroad, but also staff members along with the officials of the self-governing region. Witnessing positive examples and gaining practical know-how led to, in research participants' view, to a strengthened cooperation when planning and implementing the individual steps of the institution's transformation.

### 3.2.2 Driver 2 – Exchange of information between institutions and regional authorities

While participants generally spoke about sporadic exchange of information between institutions and officials on the regional level (see 3.3.4), some good examples were identified. Representatives of self-governing regions mentioned regular meetings of self-governing regions where they discuss issues related to provision of social services which serves also as a platform for exchange of information on the DI process.

#### **PROMISING PRACTICE**

##### **Conference *Good Practice* – our inspiration**

Conference *Good Practice* has been organised annually since 2009 by the Trnava self-governing region and the University of Trnava. The aim of the conference is to bring together different actors in the field of social and community work from academia, NGO sector, public administration and private sector to discuss current challenges and good practices in providing social and community-based services. Thus, people from different fields have an opportunity to learn from others and to establish networks for future cooperation. Several participants of the research mentioned this as a good practice enabling exchange of practice and experience.

Looking at cooperation within self-governing regions, some participants referred to dedicated meetings with representatives of the institutions they administer. Such meetings enable exchange of experiences and knowledge – from institutions already undergoing DI to others that have not initiated the DI process so far.

Within the National DI Project, several documents have been produced with an intention to guide other institutions when planning and implementing future DI activities. These documents are based on the knowledge and experiences gained during the National DI

Project and are available to general public on the website of the Implementation Agency.<sup>34</sup> However, according to actors on the local and regional level, the communication and sharing the information during the implementation of the National DI Project could have been much more intensive and some of them even consider the project as a wasted chance for mutual learning from the process (see section 3.3.5).

### 3.2.3 Driver 3 – Training workshops and consultations provided during the National DI Project

Although having many shortcomings, the training workshops and consultations provided during the National DI Project were evaluated by research participants as an important driver. Twofold positive impact was identified. First, workshops provided guidance on practical working methods and steps to be taken within the DI process. And second, they contributed to gradual change in the understanding and perceptions of people involved in DI familiarising them with differences between social services provided by institutions and CBSs.

Institutions' employees were trained in how to employ individual approach, elaborate individual plans and other new methods of work. Within the project, transformation plans were elaborated in mutual cooperation between the institutions, their administrators (regions) and project's experts.

### 3.2.4 Barrier 1 – Lack of information about the DI process and poor guidance

Research participants across all groups involved in the research, reported lack of information and guidance from the responsible state agency – the Implementation Agency of the Ministry of Labour, Social Affairs and Family. This was particularly stressed as a major problem by participants on the local level. Institutions that participated in the first National DI Project reported a failure of the Implementation Agency to communicate with them or guide them through the process, leaving them with lack of information about the future impacting on the sustainability of the process. Lack of information about the DI process was even more visible when talking to the respondents from an institution that did not take part in the National DI Project.

### 3.2.5 Barrier 2 – Lack of proper and adequate preparation

When assessing the National DI Project, participants emphasised the lack of coordination and proper preparation in addition to the long delay in launching the project, which resulted in its implementation in one and a half years instead of three. This led to chaos and significantly undermined the potential of the whole project, leaving employees overwhelmed and some of them even in shock and ending in the adverse effects of the project. As a policymaker put it:

*"I think the problem was that their notion [of the Implementation Agency] at the beginning absolutely did not correspond to the reality. As if the philosophy they adopted completely ignored the argument – 'Wait a moment, these people have never heard of deinstitutionalisation'. You see? [...] Changing people's way of thinking is the hardest thing." (Regional policymaker)*

The need to quickly finish the first project did not only mean that training workshops had to be implemented within a short timeframe; service providers saw the tight schedule and

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<sup>34</sup> Slovakia, Implementation Agency of the Ministry of Labour, Social Affairs and Family of the Slovak Republic, [Národný projekt podpora procesu deinštitucionalizácie a transformácie systému sociálnych služieb](#).

hastily implementation of the process as detrimental to its implementation. Some reported that it impacted negatively on the proper preparation of clients for the transition. Contrary to what national authorities reported in this research, service providers stressed that the process should be slower and taken in several steps.

### 3.2.6 Barrier 3 – Discontinuity in implementation of the National DI Projects

The first National DI Project<sup>35</sup> that included 10 institutions faced numerous challenges. Participants spoke, among others, about delay in launching the activities, lack of proper preparation, and hasty trainings. None of the institutions went through the physical transformation phase and no funds were drawn from the Integrated Regional Operational Programme (IROP).

This was the case also in the locality where FRA's research took place. Employees reported feeling demotivated that after attending many training workshops, there was no continuity of the DI process. As the pilot project was project-based, it lacked sustainability. A representative from an NGO reported that while the project enabled information sharing on new methods of work, there was no clear national-level commitment that the DI process will continue in the future.

Another concern raised by an NGO representative is that the discontinuity of the National DI Project may lead in practice to unsystematic implementation of DI across localities. Potential problems include, undergoing transformation without proper preparation, or developing transformation plans of lower quality, which will impact the whole process.

### 3.2.7 Barrier 4 – Lack of practical information and good practice examples

Employees of institutions also reported that training seminars did not provide enough practical information. They also lacked a continuous supervision during the process after the end of the project phase and a step-by-step "manual" on how to undergo the process. Another challenge reported by employees was the lack of good practices from other institutions or countries on how "it can be done in practice". This issue arose specifically in the inclusion of clients with severe and combined disabilities into the transformation of the institution.

*"I think that [the institutions] will not manage it alone. The new period has just started for them and if there is nobody to help them meaningfully, someone who already underwent [the process], then they cannot give up, but they will be worried."*  
(Representative of non-governmental organisation)

## 3.3 Active cooperation between the people involved in the deinstitutionalisation process

### 3.3.1 Driver 1 – Cooperation between institutions and their regional administrator

Since most of the residential institutions for people with disabilities are established by regional authorities (self-governing regions), cooperation between the institution undergoing 'transformation' and the respective office of the self-governing region is viewed as crucial.

According to representatives of institutions involved in National DI Project, the support and assistance they received from the respective self-governing regions varied largely.

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<sup>35</sup>Ibid.

Some institutions involved in the project reported having not enough support from their respective regions. Others, including the case study locality, cooperated with their founders very closely not only during the implementation of the project, but also later when they planned further steps and activities taken within the DI process. In the case study locality, the self-governing region assisted in planning the steps of the transformation phase, and later took a decision to finance the increased costs of transformation from its own budget. This was positively reflected by participants in the case study locality.

*“It [the DI process] is all up to the enthusiasts who are making it happen. And perhaps also up to individual self-governments because they are also very important in terms of providing political support and backing the process in their respective regions. For our part, I must say that since the project has had our support all along, the institution [in the DI process] has been able to achieve all that it has achieved. Had it not been for the provided support, today we would also have been in a situation that the training is over and that’s it.”* (Regional policymaker)

### 3.3.2 Driver 2 – Cooperation with other relevant stakeholders on the local level

According to the experiences of the representatives of institutions involved in DI, the institution undergoing ‘transformation’ needs to open up to the locality, establish new forms of communication and strengthen relations with other local actors. The participants outlined the following advantages. First, it is important since the institution needs to spread the information on the DI process and all aspects it entails. Second, the institution needs to explore all the relevant sources within the locality that could be engaged into the DI process, which means that the institution aims not only at the physical relocation of clients into independent/sheltered living units and looks for new properties, but also plans the services and support that are necessary for their clients once in the community.

Within the case study locality, the institution utilised the existing ties to other local actors to be able to proceed with the DI process. As for spreading the information, the institution informed other local actors at the so-called community meetings where relevant representatives of organisations active in the town regularly meet to discuss various issues. Based on the cooperation with the municipal office and funded by the administrator (self-governing region), the institution managed to buy flats for creating a supported living flat. The institution also developed cooperation with other actors, such as the local library and the Centre of Leisure Time Activities, local NGOs, informal civic associations, churches and schools in the town. With regard to the latter, a volunteer programme was developed in cooperation with the local secondary vocational school.

### 3.3.3 Driver 3 – Cooperation between institutions and NGOs and DPOs

Besides ensuring active cooperation between the institution and the respective municipal and regional authorities, engaging actively with local NGOs and DPOs is another key factor reported by participants. This was particularly stressed as pushing the process forward by service providers – both institutional and community-based – as well as by representatives of NGOs and DPOs. Three specific strands of cooperation were highlighted by research participants.

First, NGOs and DPOs play an important role in providing expert advice and know-how to institutions taking part in the first DI project. In some localities, this cooperation was reported to have continued on individual basis after the National DI Project was completed,

including in the case study locality, which involved NGO experts in the preparation of its transformation plan.

Second, participants reported that several NGOs – including SOCIA Foundation, the Social Work Advisory Board and Supported Employment Agency – played a big role in pushing the process forward by advocating for DI for several years already.<sup>36</sup>

Third, in addition to bigger national level NGOs, local NGOs also play an important role in the DI process. However, such organisations are not present in every location. Establishing local NGOs and initiatives was seen as a way to provide wider range of support for people with disabilities on the local level and to secure additional funding of activities within the DI process.

#### 3.3.4 Barrier 1 – Insufficient communication

Participants reported lack of communication from the responsible bodies, on the regional actors – responsible actors on the self-governing level – but moreover communication from the Implementation Agency of the Ministry of Labour, Social Affairs and Family. The institutions that participated in the National DI Project reported they had no contact whatsoever with the Agency after finishing the first project; they were not aware of its sustainability; any future activities; and continuation with a second project. In addition, employees reported that there is no national body to address when they encounter problems or challenges during the transformation.

According to service providers from various regions, decision makers on national, as well as regional level, are often unfamiliar with the situation of social services providers and they lack first-hand experience from the field or have experience in other types of social care. Even though they may be good managers, they are perceived as the ones taking decisions without real knowledge of the current challenges. Many service providers would welcome greater willingness to engage and hear practical voices from the ground. The lack of communication is perceived not only in the direction of national and regional bodies towards institutions, but also from regional authorities to central / national level. Service providers feel that regional self-governments do not ‘push’ enough the Ministry and don’t reach out to NGOs.

#### 3.3.5 Barrier 2 – Lack of active cooperation between national, regional and local level actors

Respondents from various levels of decision-making and practice also spoke about lack of active cooperation and coordination between levels of governance, both between national-regional, regional-local and national-local level authorities as well as between institutions themselves. When comparing and assessing the national project with the process in the Czech Republic, social services providers emphasised the lack of coordination and proper preparation, resulting in chaos and significantly undermining the potential of the whole project.

Many respondents reflected on the lack of cooperation between different levels of administration, also mentioning that the division of competences is ill-fitting. They insisted that regions have too many competences in the DI process, which makes the transparency and communication between the respective DI actors complicated and lengthy. One representative from a regional self-government, for example, pointed out that

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<sup>36</sup> The most active NGOs include: [SOCIA Foundation](#), [Social Work Advisory Board](#), Supported Employment Agency ([Agentúra podporovaného zamestnávania](#)).

municipalities are the ones knowing their citizens best and can best define what services should be provided. It is therefore unrealistic to expect a regional government to organise CBSs at a local level.

Indeed, the divergence of views among participants on who should be responsible for various activities and provision of services indicates the lack of active cooperation. For example, employees of institutions complained that they were left alone to create transformation plans, while regional level officials complained that this competence should lie within the institutions' management, as they know the locality best. This lack of overall vision of DI as a goal towards which all levels of administration should work together, supporting each other, emerged as a significant barrier in the research.

### 3.4 A change in attitudes towards persons with disabilities

#### 3.4.1 Driver 1 – Change in attitudes of the local population

Besides prejudice informed attitudes of general population towards people with disabilities, caused by their isolation in remote places, local-level participants spoke about the immense positive effect of people with disabilities leaving institutions and interacting with the local community.

What helps to counter negative perceptions and fears in the local community, according to participants, is the availability of information as well as the opportunities to meet and interact with people with disabilities in the streets, shops, other public spaces, and cultural events. Within one locality involved in the National DI Project, those people who protested massively at the beginning started to be supporters of people with disability in DI maintaining regular contacts with them. In the case study locality, people with disabilities living in the institution are well-known within the community as they participate in many local events. Similarly to other localities, it was mainly the presence of people with disabilities in the town and chance to see and meet them in the streets (and elsewhere) that helped to improve the attitudes of the general public towards them.

According to representatives of institutions, the active role of institutions in their communities acts also as a driver. By opening up the institution to wider public by, for instance, providing services also to people outside the institution and actively interacting with other actors on the local level, also leads to change in local community perceptions towards people with disabilities.

#### 3.4.2 Driver 2 – Changes in attitudes of the institution's staff towards the DI process

According to representatives of institutions and regional and local-level policymakers, the staff of institutions implementing the DI process underwent a significant change in their attitudes towards the DI process. Having many doubts and fears in the beginning, the employees started to change their working habits and methods after completing the training workshops within the National DI Project. They received a lot of new information and had an opportunity to visit transformed institutions abroad. What was also of high importance in this process, were the positive outcomes of the process they gradually observed.

*"I believe it was really when the training process was launched and we actually began to discuss what was the essence of the entire process. When we met with people, for instance from the Czech Republic, who already had their experience and who used concrete examples to [show the employees] why the existing system was not good, that was basically the moment when tables began to turn, bit by bit.*

*That's when the [institution's] director along with her team gradually began to change their employees' perception of the nature of services they provided. That was basically the moment, the education process was the moment when the information began to flow in and [the employees] began to [realise] that it really made sense for the clients to see the quality [of provided services] increase. And this information began to change them." (Regional policymaker)*

According to employees of institutions, the lives of clients involved in DI changed a lot in many positive aspects. Most of all, they developed many new skills and gained self-confidence. Seeing these positive changes in their clients' lives helped increase the motivation of employees to proceed with the DI process.

**Paul\***

I had been living in the institution since I was seven. I was chosen for the relocation to the supporting living and underwent training in the training flat. The training apartment looks like a common flat, with its own living room, kitchen, bathroom and equipment such as washing machine, unlike all other "rooms" in the institution. I learned new skills like cooking, cleaning, taking care of money.

Several months ago, other clients and I moved together to our own supported living flat in the centre of the town, where I live with five other people (two in one room). There is also one room for instructors, who have been living with us (one at a time, altogether four rotating in shifts). I was afraid of living outside of the institution for the first two weeks, but then I settled very well and now I am not afraid anymore – except for the fact of living on the highest floor. I do not want to return back; the supported-living flat is my "home". The institution is still my "place for work" since I go there every day to work in the sheltered workshop. For the future, I have a dream of being able to work as either a chef or a cleaning person in the restaurant and to have my own little house with a big kitchen.

I am particularly happy about being able to "make my own plans", decisions and choices, especially over the weekends. Although my daily plans are quite similar to what they were when I lived in the institution, now I can choose what I want to do. I have more privacy and I do not need to wake up with others very early in the morning. I can decide whether to do some writing, or sit and have some coffee in peace.

\* All names used in the report are pseudonyms.

Even if employees of institutions agreed that their acceptance of changes brought by the DI process developed a lot, according to representatives of NGOs and DPOs there is still a way to go. They comments that the change in paradigm from providing care in institutional services to providing support in the community is only partial and further training sessions and education is needed to create better and true understanding of the concept of independent living.

### 3.4.3 Driver 3 – Expectations of people with disabilities and their families that the DI process will be put into practice

The DI process in Slovakia has been already discussed for several years by public authorities, experts and other actors. That is why it has raised expectations from people with disabilities, their relatives and carers. Even if we cannot talk about a massive pressure imposed from the side of people with disabilities (DPOs, self-advocates), a representative

of a national human rights body thinks that the process has been in such a progress so far that it cannot be halted.

*“Simply, no one in this state can afford to suspend this [DI] process. I believe that no one would risk something like that. So, I think that yes, we will definitely move on to this trend, I even have information that there should be a higher number of institutions involved in this process.”* (Representative of a national human rights body)

However, it must be said that the push for DI is significantly higher on the national level compared to the situation in many locations where institutions still exist (see section 3.3.6).

#### 3.4.4 Barrier 1 –Employees attitudes

##### *Attitudes towards people with disabilities*

While employees and management of institutions generally understand what DI might mean in technical terms, not all of them were able to reflect on the ideological core of the process and the required paradigm shift from providing care to supporting people with disabilities. The embedded approach of ‘caring’ for people meant that despite having nice, caring and familial relationships with their clients, most of the employees regard them very paternalistically – like children. Many employees of institutions, participating in this research, did refer to clients as to “our kids”. As reported by a senior coordinator, this is a challenge that is hard to change. Another manager explained it as follows:

*“An employee may change as a professional, but if he/she is incapable of approaching someone as a partner, I mean personality-wise, then [...]. Such an employee is hard to find. So it's not simple and changing the people who have been working in the institutions for years, is a very hard, long-term process.”* (Manager of a social service)

##### **Martina**

My name is Martina and I am 21 years old. I was raised in a children's home in the eastern part of Slovakia [a state run home for institutional care]. Then, I don't remember when, I was placed in a Social services home. I do not maintain any contacts with my family. My family visited me only once.

I attended a special school for intellectually disabled children, which was based in the same building where I lived before my move to the supported living flat. Nowadays, I live in the supported living flat together with five other clients for already several months. The flat was bought by the Social services home during the process of DI.

Before I moved to the flat, I lived in the institution. The main difference is that in the institution I had to share a room with seven other clients – all of them were girls. The boys had a different room in the same section of the building. Now I share a room only with one girl – she is my best friend.

Last year, I was told by the director of the institution that I had been chosen as one of the six clients for DI. The director had a meeting with all of us clients and explained the process of training and moving to the flat. They provided us with information on how it would look like and what we can expect from the process. I was asked whether I would be willing to move to the flat and I agreed; I was looking forward to moving to the flat.



As the first step, we moved to a so-called “training flat”. The director – together with other staff [social workers and therapists] decided on who would be the most suitable for DI. I was very much looking forward to it and all of the other clients were happy about it, too. The director described the whole process – that we would go to the training flat to learn all the skills necessary for independent living and after that, we would move to a supported living flat, outside of the institution.

The training flat was equipped in a more modern fashion and it was cleaner and nicer than the one before. I could bring the pictures and photos and put them on the walls. Since we are only two in one room, I had more space for everything.

We had been learning how to prepare food, wash our laundry, iron our clothing, how to count money, how to go to a shop and buy things, how to buy tickets for the train or bus. Sometimes we had walks with our instructors to learn how to get oriented in the town.

A year ago, we moved to the supported living flat. We call it “home”. At the beginning, I was afraid to go there, because I could not imagine what it would look like and I did not know anybody in the neighbourhood. The flat is located high in the block of flats and at the beginning I was scared of the height. I did not even go to the balcony. Now I do.

Now I have some friends in the block of flats – three girls from the lower floor. Sometimes we have some small talk when we are waiting for the lift or when the girls play in front of the block of flats. However, I have never visited them in their homes, neither walked with them around.

I do not have keys and never spend time in the flat alone. We always have some sort of supervision or “company” of the instructor or another employee of the institution.

I would like to visit my family one day, but I don’t believe it will happen in the future. I would also like to live even more independently than now – having my own family. But I don’t know whether it is possible, it’s just my dream. My dream is to have a proper work outside the institution. I would like to work as a nurse for older people. I want to earn money since I have only pension for disabled people, which is very low.

Perceiving people with disabilities as children is also visible when discussing the topic of relationships and sexuality, as institutions rules generally do not allow a man and a woman to live together in one room.

The respondents, however, recognised that attitudes can and indeed do change with different experience and training. They also stressed that attitudes of employees, management, and officials and policymakers in all levels of administration (municipal/local, regional, national) towards people with disabilities play a crucial role in moving the process forward or holding it back, so this is a crucial issue to be addressed in the process.

#### *Abuse by employees*

Very alarmingly, some participants reported having experienced abuse by employees in some institutions in the past – either mocking them, calling them names, or even using clients to perform tasks instead of employees. These interviewees also reported that some employees directly dissuaded them from moving outside of the institution, telling them they would never be able to live alone. People with disabilities living in institutions then

suggested the motivation might have been that the employees feared they would lose the "capable" clients as helpers with their daily tasks. As one former client reported:

*"I know [a few] who are capable, back from my days at [institution's name], and they are maybe even better than I am, but the employees have not since given them the opportunity, the chance to move into a supported house. They are afraid, those employees. Even now, they still refuse to talk to me. But I did it [moving out] for my own good. [...] Everybody tried to talk me out of it, they told me I wouldn't make it, but it was only because no one wanted to work there and I could do anything."* (Person with disabilities)

#### 3.4.5 Barrier 2– Attitudes of communities and families

##### *Attitudes of the people from the community and families*

The lack of information on the DI process and moving towards support services in the community was highlighted as a major barrier across all the groups involved in the research. Firstly, there was a complete lack of national information campaign about the DI process that resulted in those towns, institutions or families having almost no knowledge about the topic. On a local level, including in the case study locality, citizens tend to think that the DI process in the institution is a mere "novelty thing" introduced by the management and do not know about links to a nation-wide strategy.

In several instances, not properly informing the public about the changes even resulted in adverse reactions and revolting local communities. Participants described several campaigns or petitions in towns, where the public opposed the DI process, or agreed with the process, but not in their own neighbourhood (NIMBY).

*"I think it works like this here. That as long as a facility has been there for 100 years [...] it's all right. But as soon as [...] they find out that something will be built and there will be 12 disabled people from the facility, they immediately start objecting: 'No, no, I don't want here anybody like them'."* (Regional policymaker)

Such attitudes were also reported by the clients with psychosocial disabilities, which in itself is very stigmatising for them:

*"In the region where I come from, [people's attitude] is a disaster. When they learn that you are mentally ill, you are done with your life. They give you no chance in life, absolutely none."* (Person with psychosocial disability)

Family members of people with disabilities also reported to be protesting against the DI process, out of lack of information, fear for their relatives or due to lack of community services.

##### *Abuse in the community*

Service providers as well as clients also reported that since people with disabilities are in more vulnerable situation, some people in the community may take advantage. Examples mentioned, included shopkeepers not giving change, neighbours using them to do their laundry or getting money from them, or sexual harassment in case of female clients.

#### 3.4.6 Barrier 4 – Fear of clients and learned dependence

People with disabilities also spoke about lack of information about DI and reported that they were afraid of the process, at least in the beginning when they did not know what to expect. Clients from some of the institutions undergoing transformation also reported that staff does not talk to them about the process, while other clients reported that employees talk to them about moving to smaller houses/flats.

There are also negative experiences of former clients, who even if willing to live independently, were not well prepared and thus encountered many challenges and lacked support. This resulted in them failing at managing their lives in the community. Having been "taken care of" all their lives, some clients are said to refuse doing daily tasks or taking responsibilities and complain about having had better life in the institution. However, there are others that surprise their former 'care-takers' with learning new skills quickly.

Participants also spoke about more measures aimed at developing independent living skills and empowerment. Being surrounded by institutional culture also means that clients have to have training sessions in making decisions and choices, being independent and also alone, planning finances and pursuing everyday daily tasks that for people who have always lived in families seem obvious. Such issues can be sometimes hard and overwhelming for clients, who fear being left alone or going alone to town. Gaining experience and getting continuous training and support, however, visibly helps clients gain confidence, learn new skills and by having "home", it ultimately helps them be happy in their lives.

### 3.5 Practical organisation of the deinstitutionalisation process

#### 3.5.1 Driver 1 – Employing new working methods and organisation of work

Institutions undergoing DI reported that they had started to use new working methods which entail, for instance, elaborating individual plans, employing personalised approach when working with individual clients, cooperating with other actors outside of the institution etc.

Looking specifically at the case study locality, employees spoke very positively that there is lower number of clients per one employee in the supported living unit compared to the situation in the 'mother' institution where one employee 'cares' for around ten clients. Experience shared by another locality show that after relocating the clients to smaller supported living units they did not need to have so many supporting staff members, since the clients are more independent and involved in conducting every day working activities like tidying up, doing their laundry, cooking, etc.

The institution in the case study locality also employs individual planning to ensure that the client receives only the support he/she needs to be able to develop his/her own potential, but also to ensure that employees rotating in the supported living unit/group approach the client in the same (very similar) way.

#### 3.5.2 Driver 2 – Higher share of professional staff to be able to create the transformation team

The experience from the field tells us that the DI process is easier to initiate in the institutions with higher share of professional staff, the research participants reported. This was also the case with the institution in the case study locality, as the institution was

originally established for children and employed also professionals like a special pedagogue or a psychologist, which was not usual in institutions for adults. In addition, the founder of the institution decided to finance a higher number of staff compared to other institutions.

One of the participants summarised that a critical number of employees is needed to persuade others to start with the implementation of necessary changes:

*“A certain number of employees who believe in [the idea of DI], so they form a core that is able to break the stereotype. In short, [the institution] is run in a certain manner and if they are strong enough, they manage to start to go the other way. Otherwise they will be overrun by the stereotype of providing social service.”*  
(Representative of a non-governmental organisation)

Another aspect of higher professionalisation of the institution's staff was viewed as a driver of change, mainly due to exchange between generations. Newcomers to social services are more open to new and experimental working methods than long-term employees. First, they possess more up to date knowledge of working methods gained during their study; second, they are not used to stable and sometimes rigid working habits.

*“The young people, the junior employees, are not burdened by the old system anymore. They have a different way of thinking than the senior ones. They are more open to new challenges and they like to try new things whenever they have a chance. Also, they are like friends with the clients. It normally happens that a staff member takes a client to the movies in the evening.”* (Regional policymaker)

### 3.5.3 Driver 3 – Funds available to cover the increased costs necessary for the transformation phase

According to participants of various categories, EU funds available for the DI process catalysed the already planned process in spite of many shortcomings (see barriers below).

Institutions, and their administrators, mainly rely on EU funds when financing the DI process. Once the funds were available, they agreed to take part in the National DI Project and initiated the process. However, the process in the case study locality went even further, since the self-governing region decided to finance additional steps after the National DI Project was over.

*“Well, what I see there is that the whole process lies in the fact that there are some EU funds and let's spend them [...]. The state is absolutely not interested in dealing with it – preparing the conditions and co-financing it with the European funds. Today it's precisely opposite. Some money came, so we have to spend it and then what?”* (Employee of a social service)

In another locality, the institution went through the transformation process thanks to managing its own funds (provided by the administrator) and other funds donated mainly by international NGOs.

### 3.5.4 Barrier 1 – Lack of finances for transformation of institutions and CBSs and their sustainability

Participants stressed that during the transition period, costs will be higher, when both service models would require funding.

*"When you embark on such a fundamental change [as the DI process], you have to finance two parallel systems. So, [for some time you have to divide] available funds between both systems before the new system begins to work; [until then] you cannot close down the previous system, but you have to finance both before the new ones start to operate. And not even the EU structural funds envisaged that." (Regional policymaker)*

On a local level, towns carry the responsibility to provide community-based services, but generally fail to do so, most research participants reported. The lack of support services along with the lack of information to families and carers of people with disabilities results in the continued institutionalisation, including long waiting lists for institutions for people with disabilities and institutions for older people.

Therefore, lack of finances transposes in two ways – first, lack of finances or not proper use of funds to support deinstitutionalisation efforts and second, lack of finances for developing community-based services.

Participants argued that the system is currently not set up well towards community services and is in need of a big reform. Funds are also not given directly to social-service users who could then choose the service they prefer, but instead funds are distributed to service providers, including to institutions. Self-governing regions as well as municipalities also still fund institutions from their own budgets. This is also particularly the case in terms of financing institutions for older people. This results in less local budget availability for financing community-based services:

*"Deinstitutionalisation should at some point also touch institutions for seniors. It must be said that hand in hand with DI, we need to talk about community-based services, their development and their support. Actually, this is still a stumbling block that there is still a large amount of money that continues to flow into the residential services due to the fact that there is a large group of seniors and the willingness to change the flow towards the community services is small to none." (Representative of a non-governmental organisation)*

People with disabilities themselves also reported there is a lack of finances for them to be able to live in the community – they do not receive enough benefits and have no jobs. Especially those that live in social care institutions, are placed under guardianship, have debts, or receive disability pension, cannot find a job, so they cannot move out of the institutions by themselves, even if they would want to. In addition, services in the community, such as hairdresser, cinema etc, remain unaffordable and inaccessible for people with disabilities, whose income ranges around 200 EUR per month and after paying the rent, they may not have money for anything else.

### 3.5.5 Barrier 2 – Lack of community-based services and inaccessible general services

Hand in hand with the lack of financing for the DI process, another barrier emerging from the research is the overall lack of community-based services. This results in clients still availing of the services provided by institutions even after moving to supported-living houses. The senior manager of one institution described this as follows:

*"I am already doing it, I already have small houses, but without having community services in the town it cannot work. [...] in fact, they will be living supposedly independently, in those houses [t]hey won't be in a large institution, and that's fine as well. But we continue providing all services to them [in the institution],*

*because we have no other possibility. They have nowhere to go for those community services.” (Manager of a social service)*

The case study locality is a typical example of a smaller locality with almost a complete lack of community-based services/field social services. Considering the lacking CBSs as a serious obstacle for the DI process within the locality, the participants stressed the need for establishing new types of social services within the town. Participants called for CBSs created and provided for by the municipality, or CBSs could be founded by the ‘mother’ institution and could be founded in cooperation with wider range of actors involving local NGOs, churches, civic initiatives, etc.

In the case study locality, the plan is to close one part of the institution where clients with lower level of impairments live and rebuild it into the centre of provision of services (such as rehabilitation, physical therapy, massages) for general public as well as for people with disabilities clients of the institution.

Participants also reported that in addition to lack of CBSs, there is also lack of variety and range of different support options. They spoke of unavailability of any home support and lack of other types of services – such as day care centres, outpatient care, assistants, school assistants or respite services.

In addition, the services that are already available, including services for general public (such as transportation or housing) are often inaccessible, as argued by one person with disability:

*“To all people I'd like to say this one thing. I mean, [...] these people in wheelchairs [...] they must struggle with bad sidewalks all over Slovakia, bad street [pavements], bad bus stops. And [some people] even laugh at them because they don't communicate with people in wheelchairs like they would communicate with me, but they mock them for not having their legs or for having bad legs.” (Person with disabilities)*

A person with physical disabilities using a wheelchair further argued that such combination of unavailability of CBSs and lack of general accessible environment precludes him from living in the community. If he had a personal assistant, it would allow him to leave a supported living house and live alone independently with his partner in their own flat.

However, general public seems to reflect on this issue as well – representatives of the local community interviewed in the case study locality reported that their town is not “disability-friendly” and that it is very complicated to use a wheelchair in the streets and difficult to attend cinema or other cultural activities.

### 3.5.6 Barrier 3 – Lack of opportunities for further integration

Another type of barrier involves the lack of opportunities for further integration, even for the clients who already moved one step forward in the DI process, and live in a supported-living flat. The case study locality was an example of a type of a town with a big lack of such possibilities – even if the clients do attend cultural events with other citizens, there is a general lack of possibilities for employment, even more for people with disabilities, although some clients told us that they desired working.

Finding a job was difficult also to the respondents coming from the regions with available options; it is very difficult to acquire jobs for the clients, as they face prejudices from employers and officials. The examples mentioned included Labour Offices denying

possibility to register them as job seekers (therefore discriminating them based on their disability and status as a pensioner).

**Peter**

My name is Peter and I come from a village in the eastern part of Slovakia. I still have a grandmother there, who I occasionally visit.

Before coming to the social services home in [...], I lived in a children's home in a nearby town. Looking back, I mainly remember the strict rules applied in the children's home. I was allowed to go out only for two hours a day and if I broke those rules, I was sanctioned (was not allowed to go out the next day).

When I was 18, I had to leave the children's home since according to the rules if somebody finishes his education and becomes adult he has to leave. The director of the children's home arranged for me to move to a social services home.

I currently live in the supported living flat operated by the institution. I share my bedroom with one roommate, which does not allow me to have the privacy I dream of. The kitchen is next to my bedroom, we make together our own breakfast there. After breakfast, I go to the workroom placed in the institution. We make various handmade products that are then sold at the local markets.

Since I have been living in the supported living, I can go out unaccompanied. However, I cannot leave unnoticed, as this supported living is within the institution without any separate entrance. I also must announce the social worker when I want to go out. Sometimes I visit the Centre of Leisure Time in the town that runs leisure time activities for the institution's clients, usually once or twice a week.

I regularly visit the Labour Office in the nearby town. I have to go there, since I am unemployed and I regularly meet the official to get job offers or other activities aimed at finding job. A year ago, I finished a nursing course organised by the Labour Office. Thus, I could be employed as a caregiver, but because of the high unemployment in the locality, I still have not been able to find a job. Before completing the course, I was allowed to do only some assistance to caregivers, for example doing the laundry, giving clients something to drink. Before I attended the course, I was not allowed to feed clients, the course is necessary for feeding.

I would like to work as a caregiver; I want to utilise the education I got during the course. Within the institution, I had worked as a caregiver and as a handyman. I also applied for a job outside the institution, but have not been successful yet.

Not being formally in the DI process, I did not get training or consultations on the DI process. My current situation allows me to make small everyday decisions mainly on what I am going to do during the day.

Choice and control I have over my life is limited because I am almost without any income. I receive just small social benefits and sometimes also irregular salary for occasional working activities. Without almost any income, I am not even able to go out for a meal, to go shopping, etc.

In the future, I would like to find a job and to live outside of the institution, e.g. in a small flat. I prefer to live there alone. I can even imagine moving to another town, e.g. to Bratislava since there are more job opportunities and higher salaries. I also think that

as many other people from the town I could also go abroad to work as a caregiver there. However, I am aware that it might be difficult since I do not speak any foreign language.

Another issue for the clients is to have a continuous support after the transition – care providers and clients emphasised that personalised support, e.g. in form of a personal assistant or a supervisor is needed also after a successful transformation. In some cases, the shortage of personal assistants prevents clients from undergoing DI process, in others, it hinders their opportunities to take part in everyday life even when living independently.

### 3.5.7 Barrier 4 – Deprivation of legal capacity

A major barrier, highlighted by experts, NGOs, the employees of institutions, as well as people with disabilities, themselves, is deprivation of legal capacity. Guardianship directly affects lives of people with disabilities, limits their independence and deprives them of the right to choose. Participants argued that all or almost all people living in institutions have been deprived of their legal capacity, with the director of the institution generally acting as guardian for all the clients. In our researched locality, this was the case of 100 % of clients.

Even though the representatives of the facilities reported to be trying to acquire their clients' legal capacity restored, it is a lengthy administrative procedure which can be sometimes discomfoting for the clients due to the psychological and intelligence assessments. Moreover, in the initial stages of the process, they experienced resistance from the courts and psychiatrists, although they say the cooperation is slightly improving.

*"Restoration of legal capacity, as I realised that with [name] [with whom] we did for the first time that the examination at the psychiatrist was horrible. She was so devastated that I said to myself: I can't do this to them. They tried them with hard mathematical exercises, they wanted to know all the presidents, good that not the American one, such abilities that it seemed absurd to me." (Manager of a social service)*

For clients, incapacitation is very limiting and strips them of their rights as persons – in legal matters, finances, employment possibility, everyday choices and decision-making with regard to very private matters, such as personal life and right to marry. It is also a matter of personal self-worth and dignity:

*"[But] for them it also holds psychological [meaning]; as soon as they see some of their restrictions partially abolished, let alone gaining full legal capacity, they view it as something truly amazing. For instance, we have a couple that want to get married, but they are not allowed to." (Regional policymaker)*

According to the social homes employees in addition to direct devastating effect on people with disabilities, by depriving them of possibility to make their own decisions, having the institution and the institutions director act as a guardian, puts the caregivers at risk, as they are fully responsible for the adults in their care. Accordingly, the social workers are then afraid to give them more independence, e.g. leaving them to go alone on the street, for in case something happens to them, the institution would be the one held responsible.

Participants also talked about the cases when people are routinely put into a category of a high level of dependence (category 6), which means they wouldn't be able to eat and dress by themselves, which is in reality not true. Therefore, as some examples given show, there are some clients in institutions who were somehow assessed as highly dependent (and thus incapacitated), but are largely independent and, according to the respondents,



do not belong to institutions at all. The concrete example said was then a case of a couple, previously assessed as highly dependent and living in the institution. After going through the process of DI, they now live in their own rented flat almost independently with little support.

### 3.5.8 Barrier 5 – Barriers in legal setting and bureaucratic burden

Participants also discussed the legislative barriers and overall bureaucratic procedures as a barrier to the DI process. They spoke about unrealistic hygienic standards for supported living flats, cumbersome public procurement procedures when trying to buy supported living housing, non-enforceability of community-based services or non-flexible legislation in case of supported living.

Another type of issue that was often reported was the need for assessment procedure on the ability to receive social services. A regional government's representative assessed them as being obsolete and old.

There is also a need of assessment to live independently. It was reported that clients who wish to live independently in supported living flats need a positive assessment from the self-governing region office. This was reported by the clients in cases where there are free places in the community-based alternatives for living. This creates fear and dependence on the regional office assessment. While the assessment is not needed in case an institution goes through transformation process (when creating CBSs for its own clients), it puts people willing to live in supported living unable to do so.

## 3.6 Cross-cutting issues

### 3.6.1 Impact of different types and degrees of impairment on the deinstitutionalisation process

Many participants across categories, including representatives of administration, management, employees, general public, as well as people with disabilities themselves, perceive DI as a process "not suitable for everyone" and should exclude people with severe and combined disabilities. They see DI as a process aimed only at people with mild forms of disabilities, or as participants often said – it is for "the capable ones". However, there were respondents that strongly criticised not including people with severe disabilities in the DI process. Such criticism was voiced by experts (even if they claimed their views were not united), some managers of institutions, some regional representatives as well as representatives of NGOs working in the topic.

Other categories of people with disabilities were viewed by respondents as not suitable for the DI process as well – these categories include people with psychosocial disabilities, people with Alzheimer's and people with aggressive behaviour.

#### *Clients with psychosocial disabilities*

Some respondents claimed that people with psychosocial disabilities, in particular those with schizophrenia, behavioural disorders, aggressive behaviour symptoms, self-inflicted injuries or problems with alcoholism are not suitable for independent living. They reported there is also lack of services for people in need of an increased psychiatric supervision.

*"We couldn't let him [person with a psychiatric diagnosis and aggressive behaviour] join the others. Everybody seemed to pose a threat for him. The*

*question is whether this client should be placed in a social services home.”*  
(Regional policymaker)

People with psychosocial disabilities, interviewed in this research, reported facing high level of stigmatisation and prejudice.

*Clients with severe intellectual and combined disabilities, clients that are bed-bound*

Participants across categories agreed that the DI process is beneficial to all clients and that they could live independently in the community, under the condition that there are enough services and support. However, a large number of respondents shared an opinion that people with severe intellectual and combined disabilities or bed-bound clients are not “suitable” for DI and are better-off in the institution. The objective should be to improve their quality of their life by providing the required services within the institutions. In their view, “moving” them would not be beneficial, and would even be detrimental to them.

*“Based on my experience, I would not [recommend it to] just anybody, because again, they have everything they need at the institution, especially the physiotherapy, [...] you don’t have the kind of conditions at the apartment that you have at the institution. And we have some [clients] with really serious intellectual disabilities and we have managed to help them improve the quality of their lives through therapies and physiotherapy; I mean, they didn’t have anybody to exercise with them or tend to them in their home environment.”* (Employee of a social service)

The view that those clients with severe and combined disabilities are not “suitable” or “capable” for the DI process was widely shared across different groups of participants. Notably, people with disabilities who have gone through the transition from institutions to CBSs, saw this as a reward for their capabilities, and not as their human right.

Many participants also seemed to understand living independently to mean living alone without support. Therefore people with severe disabilities are not able to live independently, since they will never be able to cook or clean up and the employees would need to do it instead of them anyway, but in a different “place”.

*“The employees have such a sceptical view [towards DI for people with severe disabilities]. That we would only move them from one bed to another. Like that. And what will we change by moving them. After all, they won’t be doing anything, they will be only lying all the time, in that room again. They could stay like this in the institution.”* (Employee of a social service)

*People with physical disabilities*

People with physical disabilities reported a number of challenges they face of living in the community. They spoke about inaccessible public transport and living arrangements, as well as lack of community-based social services, such as personal assistance.

### 3.6.2 Impact of age on the deinstitutionalisation process

*Older people*

In addition to different types and degrees of impairment, age was also seen as an influential factor for achieving DI. Many participants perceived that the process is more

difficult for older people in general and for those with disabilities in particular, and many concluded that it is not suitable for them at all.

Lack of community-based services is particularly worrisome for family members of people with disabilities who take care of their children or relative with disabilities at home. Many spoke of their own increased age which will impact their ability to take care of their children. Therefore they see institutionalisation as the only option:

*“And often when a family runs into some sort of situation that requires an urgent solution, the supply is so trimmed and limited and the system is so deeply rooted that they often see [institutional care] as the easiest solution to apply for. Last but not least, it needs to be said that when you come to the authorities in order to solve this kind of situation, you often receive very limited information. As a result, people have [developed] some kind of notion [of these services] and they cannot even imagine how it could work differently because they have never experienced it.”* (Representative of a non-governmental organisation)

Therefore, since families and their relatives are used to institutions that provide social services and perceive them as stable and trustworthy, abolishing or altering them encounters opposition. Although the DI process should at some point also include institutions for older people (with and without disabilities), there is still a great reluctance to change the system of provision of services towards such based in the community and thus, large amount of funding continues to flow into institution settings.

#### *Children*

While it is currently not possible to accept new persons under the age of 18 into institutions for people with disabilities, there is still a very large number of children in such institutions. In addition, children with disabilities are still institutionalised in children´s homes. There are big issues with long-term institutionalisation of children with disabilities that after gaining maturity usually go to social services institutions where their conditions largely deteriorate:

*“In foster care houses (children’s homes) we have about five hundred of these children [with disabilities] who will, following this way, end in social services. When they are eighteen, they go from foster care to institutions. In foster care [children’s homes], they at least care somehow, do something with them, and then it gets all killed in social services institutions.”* (Representative of a non-governmental organisation)

## 4. MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION

### 4.1 Commitment to deinstitutionalisation

Participant in the research across stakeholder groups agreed that commitment on the national level to the DI process is a crucial prerequisite for its successful implementation. It is vital that key state representatives officially declare their commitment for systemic change from institutional to community-based services. Such commitment could be, for instance, declared in a Government Programme Manifesto.

*„The fact that it's in the government programme manifesto, for instance care for persons with disabilities where one of the tasks, for example, would be that the Slovak Republic will reduce the number of large-scale institutions by half by 2020. That means some specific measures that will lead to [...] I don't know, as if the Slovak Republic declared its will to provide different types of services to persons with disabilities than it is providing now.“ (Regional policymaker)*

A significant role in securing government's commitment could be played by strong NGOs that advocate towards the government and highlight the importance of DI. A similar role was played by an NGO in the process of deinstitutionalisation of foster care. The service providers suggested that this was one of the success factors in the process. However, there is no such an influential NGO representing interests of persons with disabilities as of now.

With respect to commitment to DI, peer review meeting participants stressed as important that various actors, particularly national-level policymakers, have sufficient knowledge of the Convention on the Rights of Persons with Disabilities. Still, not all actors involved in DI understand the concept of independent living. The role of national-level policymakers is seen as crucial in fostering a common understanding across stakeholder groups, since they carry the responsibility to implement the CRPD and ultimately spread information further to lower levels of public administration.

#### 4.1.1 Clarification of responsibilities for implementation of DI

Regional-level stakeholders perceived they had too many responsibilities and urged the Ministry to take on more practical tasks with respect to DI. Contrary, the Ministry saw its role in policy making and legislative actions, while DI should be practically implemented by self-governing regions.

Self-governing regions called for the Ministry to take a more active approach, for example by establishing a task force on the ministerial level to coordinate DI activities on all levels, particularly with regard to education and training. Such action will also show stronger declaration and greater commitment to DI by the state.

### 4.2 Availability of guidance to support the deinstitutionalisation process

The need for support and guidance was a topic discussed first and foremost among the regional and local actors and service providers. These groups agreed they would need much more support from the Ministry in the DI process. Regional-level stakeholders, which took part in the first National DI Project called for a functional Implementation Agency that would be able to provide feedback on the individual transformation plans.

#### 4.2.1 Guidance for front-line carers

Service providers felt overwhelmed with the transformation processes and thought that institutions cannot implement transformation plans on their own.

Apart from calling for greater support from the Ministry, service providers also stressed that they need more support from self-governing regions as they are their founders and administrators. This was seconded also by a regional stakeholder who indicated that the lack support from the Ministry could be partially supplied and ensured by self-governing regions themselves, particularly in the form of soft measures such as training of institutional staff and sharing of experience. Education, training, awareness-raising activities and practical information on DI targeting front-line carers is of utmost importance also according to the service providers. However, it was not clear who should be responsible for provision of such guidance.

#### 4.2.2 More active coordination by the Ministry

Service providers and the regional level actors suggested it would be helpful to have a contact person at the Ministry responsible for coordination of DI whom they could consult when required. The coordination of DI should be executed by the Ministry. It should be, however, a continuous process going beyond the timeframe of a national project. Regional-level stakeholders would welcome similar assistance also when applying for EU funds. One regional level stakeholder provided a concrete suggestion that the Ministry could create expert teams that would help self-governing regions with preparation of grant applications since the application process is currently very complicated.

#### 4.2.3 Sharing of good practices

Research participants also proposed that sharing of good practices should be fostered as it serves as a good way to raise awareness among employees. This includes experience exchange both within Slovakia but also from abroad. The system of top-down passing of information (i.e. from the national to the local level) would need significant improvements as well as it is almost non-existent at the moment.

Overall, local and regional actors would welcome if the state took more responsibility for the DI process, particularly with regard to coordination of the process as well as of its financing. Both municipalities and regional self-governments had no objections to their role of practical implementation of DI, but needed more guidance, support and coordination from the national level.

### 4.3 Active cooperation between the people involved in the deinstitutionalisation process

Participants in the research underlines that achieving successful implementation of DI requires inter-sectoral cooperation and cooperation of actors on different levels of administration. To ensure the later – cross-governance cooperation, actors called for involvement of regional stakeholders and service providers in coordination meetings at the ministerial level, particularly during the implementation of the National DI Project.

Actors who had direct role in implementing the first National DI Project would have welcomed more intensive and regular communication with the Ministry during its implementation. According to a representative of a self-governing region, a sustainable communication platform would have been very beneficial.

#### 4.3.1 Coordination of cooperation among actors of DI on the local level

On the local level, different actors have different competencies and they do not cooperate adequately. It does not mean that such cooperation is impossible; it only needs a strong coordination, e.g. by the regional self-government office. Service providers, in particular, stressed that the DI process requires more intensive integration across different aspects. The practical field experience and know-how should be transferred both to the academia and policy making via improved communication among the actors on the national and regional levels and service providers on the ground. That, however, requires coordination.

Furthermore, service providers suggested that greater cooperation with local NGOs and community service providers on the local level would be beneficial. It would help to transfer good practices from daily practice and would also lessen the burden laid on institutions during DI.

#### 4.4 A change in attitudes towards persons with disabilities

##### 4.4.1 Change in attitudes of the general public

All groups of respondents agreed on the need to bring experiences of persons with disabilities closer to the general public. Responsibility for this task should lie with the Ministry. A regional level stakeholder suggested launching a national or regional campaign in media informing on the DI process.

*"We said it within the National Project – that national campaign is lacking. And that cannot be done by the Implementation Agency, it must be done by the Ministry. The campaign should run on all levels towards the public using some popular means of communication. But also on the regional and municipal level, and the Association of Towns and Communities."* (Representative of a non-governmental organisation)

Respondents recommended that the campaign should contain individual stories of persons with disabilities.

According to some of the research participants, mainly representatives of NGOs, it is necessary to emphasise that DI is a human rights issue and this knowledge should be systematically widespread among all actors involved in the DI process. Actors on the national level should be the first ones who understand the key terms and concepts and are then responsible for spread this information further. Therefore systematic trainings on the Convention on Rights of Persons with Disabilities and the right to independent living are important.

##### 4.4.2 Change in attitudes of local populations

As indicated by municipal actors, in order to change attitudes of local populations continuous discussion from the beginning of the process with them aiming at explaining the importance of DI is crucial. A few concrete suggestions of how this can be done were formulated. For instance, by holding meetings of persons with disabilities and their future neighbours (in case of moving persons with disabilities into supported living flats in local neighbourhoods). A representative in one municipality suggested that local/town administrations can play a significant role through their working groups for the development of local plan of community services.

The most effective way to change local populations' attitudes is the creation of space where they can meet persons with disabilities and get to know each other. This was agreed upon by both municipal stakeholder and service providers. Institutions should therefore be more open towards local communities, participants suggested.

*"The town has accepted them. For instance, [I remember] at the very beginning when we took all those wheelchairs outside because that was our clientele, then we began to take our clients for walks around the town and everybody was giving us these stares, it was [not very pleasant], right? And now it is not [like that] anymore; now everybody takes it as a regular thing."* (Employee of a social service)

A DPO representative suggested as beneficial the creation of inter-sectoral teams at the local level that should involve local authorities, representatives of institutions and CBSs, schools, NGOs and individual citizens. The participant also emphasised the crucial role of employees of the institution in communicating with the local communities. They could spread the information in their immediate environment, among their family members, friends, etc. However, employees of institutions would need more information themselves.

#### 4.4.3 Change in attitudes of employees

Participants agreed it was important to work with attitudes of employees of institutions as well and thus prevent their resistance to DI. This could be achieved by more training workshops and education provided by self-governing regions, for instance, and by sharing good practices either from other locations or from abroad. Employees of centres for social services are often reluctant to any change in their working habits. If they see positive outcomes of deinstitutionalisation, they become more open to it. This was agreed upon also by the representatives of institutions who said their employees needed more information on DI and sources of inspiration that it works.

### 4.5 Practical organisation of the deinstitutionalisation process

#### 4.5.1 Legislative changes

Majority of participants across groups, but mainly national and regional-level stakeholders and services providers, called for legislative amendments. The law regulating the provision of social services should be amended so as to define new social services (particularly CBSs). CBSs are slowly being created, because there is a demand but the legislation does not reflect these changes and does not regulate their operation.

According to one research participants, representative of an NGO, the definition of social services provided in the law is problematic and it would be helpful to harmonize Slovak and European legislation. Nowadays social services are understood by existing laws as economic activity and this fact complicates the use of EU funds for DI since the drawing of EU funds needs to be in compliance with rules of economic competition otherwise it is seen as an unlawful state aid. If social services were defined as services in general economic public interest, other rules for using EU funds would be applied, which would make the drawing of EU funds much easier compared to the present situation. Concretely, Act no. 448/2008 Call on social services could provide such a definition of social services as services in general economic interest.

#### 4.5.2 Change in the system of funding

The funding of social services was a widely criticized feature and the need for its change was agreed upon by literally all participants in this research. Both in individual interviews

and in focus groups discussions – on the national level and in the case study locality – many spoke about introducing *per capita* funding instead of the current system of funding per institution. That would enable service providers to provide more individualised care in accordance with their clients' actual needs.

*"To me, an ideal system of funding is a personal budget, that is some personal budget or benefits according to one's extent of dependence."* (National policymaker)

At the same time, *per capita* funding allows for more flexibility in service provision which would be appreciated by service providers. Furthermore some argued that *per capita* funding is less costly in the long run than *per institution* funding. Several respondents suggested that the state should see funding of DI as a social investment, even though the transition period (funding *de facto* two systems – old and new) is costlier. This is also linked to the need to implement DI as a process not as a project which is limited in time.

With respect to funding, participants called for a functional system of drawing the EU funds. In particular, they stressed that the grant application process should be made more efficient and state should create conditions for drawing the EU funds that can actually be met by those who need such funding. Given that the EU funds represent a significant source of DI funding, there is a need for simpler rules of their use, particularly with respect to the processes of public procurement. Such processes are often lengthy and too complicated slowing down the DI process significantly, as reported by regional-level stakeholders.

#### 4.5.3 Creation of community-based services

Participants across all groups agreed that successful implementation of DI necessarily requires a creation of a range of CBSs that would be provided in the clients' natural environment, but are completely lacking at the moment. Service providers, in particular, called for a network of community services and said that creation of CBS should precede DI itself. However, functional CBSs are contingent upon sustainable funding.

There were divergent views as to where the responsibility for creation of CBSs lays. One participant indicated they should be created by municipalities, another – a representative of a DPO – thought CBSs should be created by institutions as part of their transformation plans. Furthermore, a regional-level stakeholder thought DI would benefit from greater diversity of CBSs providers on the local level. CBSs should therefore be provided by various actors (not only self-governing regions and municipalities) in order to secure variety of the offer. This is also linked to the question of redistribution of competencies in the DI process.

Regional-level stakeholders felt overwhelmed by the share of responsibility they had been given within the DI process. Their competencies should therefore be redistributed between regional self-governments and municipalities. More specifically, municipalities should be responsible for organisation and provision of CBSs.

Furthermore, participants called for greater involvement of other actors (civic society such as church, NGOs, community initiatives) in service provision. CBSs thus should not only be provided on a community level, but first and foremost by community actors. This would allow clients to have more freedom of choice when deciding for a particular service.

*"Well, since we are talking about community social services, I really believe there should be an entire spectrum [of providers]. And [I would be inclined toward] non-*



*public providers. I mean, they are able [to saturate the actual demand], for instance many church organisations or certain interest [associations]. They are able to provide [various services] and lend these services a different dimension. After all, we want the clients to be free in terms of choosing where they will go."*  
(Regional policymaker)

Looking at the case study locality, participants in the research outlined a number of community-based services which are needed: a community centre, greater out-patient nursing service, a system of social employment, but also a day-care centre for families with children with disabilities. It is also needed to extend health care and psycho-social community services to make them available to all who need them. The locality would also benefit from more units of supported living located outside of the institutions, ideally in houses, not in blocks of flats.

#### 4.5.4 Assessment of the quality of social services

The assessment of quality of social services, set by the Act no. 448/2008 Call on social services, has been postponed several times already – according to research participants. They see it is as crucial to already start with evaluation of quality since it is very likely that the existing institutions will not be able to meet the quality criteria. This could speed the necessary changes in provision of social services.

#### 4.6 Responsibility for implementation of deinstitutionalisation

The research findings show that there are significant differences in views of the individual actors on competences and responsibilities to implement the DI process.

Representatives of national authorities – the Ministry of Labour, Social Affairs and Family is responsible mainly for drafting legislation and policy documents. In the Ministry's view, the founders of social service providers (self-governing regions and municipalities) should act in compliance with legislation and national conceptual documents and put the Ministry's strategy of DI into practice.

Representatives of self-governing regions – the Ministry of Labour, Social Affairs and Family is responsible for a proper coordination of the DI process and should also cover the increased costs of the whole process to a greater extent. The Ministry should also communicate with self-governing regions when planning and coordinating the DI process, which is currently not happening.

Representatives of social services providers – at the moment, the Ministry of Labour, Social Affairs and Family fails in its role of a coordinator of the DI process. The Ministry should coordinate the process more closely, so that it can be implemented continuously; it should establish a job position or a department that would deal with coordination of DI. The Ministry should also reflect on the increased costs of the DI process and earmark funds to cover them.

Representatives of NGOs/DPOs – The Ministry of Labour, Social Affairs and Family has competences to create favourable conditions for the DI process within which also the situation of CBSs and small social service providers should be improved, since now they are struggling for survival. The more CBSs would be available in localities, the more easily the DI process would be implemented. The lack of CBSs could be solved by establishing new social services by municipalities, 'mother' institutions or other actors – such as church, NGOs – on the local level.

Representatives of municipalities – According to representatives of municipalities the implementation of the DI process is not in their competence. They are often reluctant to be more involved in DI, since they fear reactions by the local populations. Furthermore, they are afraid they would have to fund more social services from their own budgets. According to them, deinstitutionalisation is mainly in the competence of regional and national authorities.

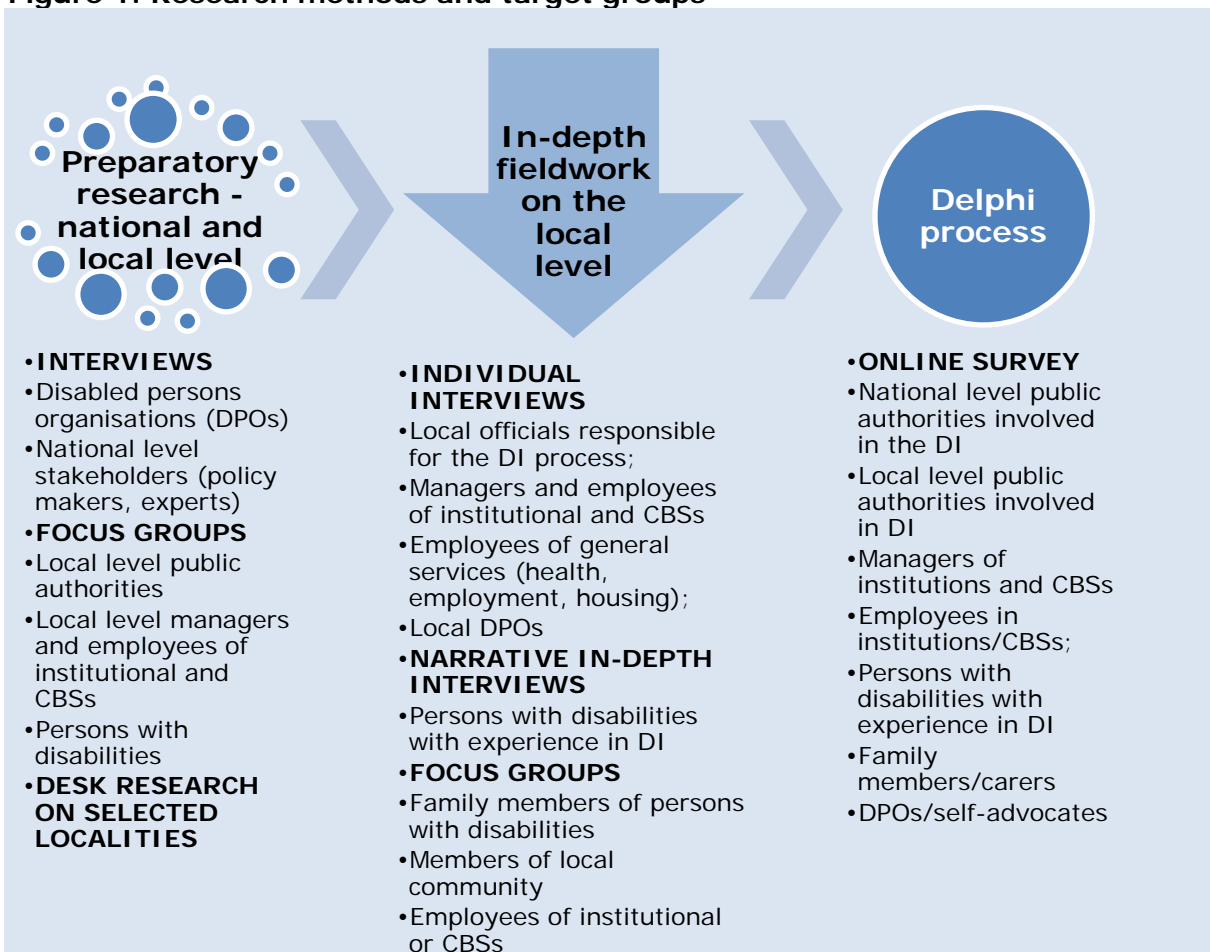
## ANNEX: RESEARCH METHODOLOGY

The fieldwork employed several common qualitative research methods to capture the views of a variety of different stakeholders. These included participatory research methodologies enabling full participation of persons with disabilities:

- Preparatory **semi-structured interviews** with selected national stakeholders to gather contextual information about the status of the national deinstitutionalisation process and to identify key themes to be explored in later interviews.
- **Focus group discussions** to explore differences and commonalities in the experiences and perceptions of groups of participants with similar roles in the deinstitutionalisation process.
- **Face-to-face semi-structured interviews** with individuals involved in the deinstitutionalisation process in the case study locality to gather their views about what works and what does not work regarding policies and practices.
- **Narrative interviews** giving persons with disabilities the opportunity to share their experience of the deinstitutionalisation process and how it affects their lives.

Much more information on the design and methods of the fieldwork research is available in the main report [‘From institutions to community living for persons with disabilities: perspectives from the ground’](#).

**Figure 1: Research methods and target groups**



Source: FRA, 2018

## Inclusion of persons with disabilities

Participatory research principles guided the development of the research design. Particular attention focused on ensuring that persons with disabilities are active participants at all stages of the research.

In preparation for the research, FRA held an international expert meeting with representatives of disabled persons organisations (DPOs) and experts with experience of conducting research with persons with disabilities. This was complemented by a similar process at the national level, where researchers in the fieldwork countries conducted consultations and interviews with national DPOs and experts.

FRA ensured the preparation of easy-read research materials and reasonable accommodation in all activities part of the research.

The names of persons with disabilities telling their personal stories of deinstitutionalisation are pseudonyms.

## Delphi process

To validate the results of the fieldwork research at both the national and local levels, FRA carried out a Delphi survey. Delphi is a participatory group communication process which aims to conduct a detailed examination of a specific issue, bringing together a range of stakeholders in a time-efficient way. The process enabled FRA to assess areas of consensus and disagreement between and across stakeholder groups and countries.<sup>37</sup>

FRA's Delphi survey included almost all those who had participated in the fieldwork. Participants were presented with a summary of the key findings and asked to identify the most important drivers and barriers of the deinstitutionalisation process.

## Peer review meeting

In addition, FRA organised in-country peer review meetings in each of the five fieldwork countries between December 2017 and February 2018. These meetings allowed a small number of research participants to reflect on the findings emerging from the research.

Discussions at these peer review meetings fed into the revision of the national case study reports and informed the drafting of the main report bringing together the findings from the five countries where the research took place.

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<sup>37</sup> Hsu, Chia-Chien and Sanford, A., Brian (2007), [The Delphi Technique: Making Sense of Consensus](#)[The Delphi Technique: Making Sense of Consensus](#), Practical Assessment, Research and Evaluation, No. 10/12; Cuhls, K. (2005) [The Delphi Method](#)[The Delphi Method](#), Fraunhofer Institute for System and Innovation Research ISI.