

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

Case study report: Bulgaria  
2018

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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 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.

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

Other relevant reports previously published by FRA include:

<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](#), p. 27.

<sup>2</sup> FRA (2017), [Summary overview of types of institutional and community-based services for persons 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.

- [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 Bulgaria. 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 Ireland, as experienced by participants in the research. It then looks at what participants believe is needed to make deinstitutionalisation a reality.

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

<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>.

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

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

Source: FRA, 2018

## 1. CONTEXT OF DEINSTITUTIONALISATION

Deinstitutionalisation in Bulgaria can be broadly viewed in Bulgaria's process of transition from totalitarianism to democracy and within its accession to the EU in 2007. The need of change in the institutional approach of taking care of people with disabilities was triggered by a BBC documentary "Bulgaria's Abandoned Children"<sup>8</sup> which provoked immense backlash both in-house and internationally. The case of Mogilino, shown in the documentary, pre-defined the starting of the process prioritising deinstitutionalisation of children with disabilities and children aged under 3 years. The DI process of children was initiated in 2010 and, by end-October 2017, the number of children living in institutions fell by over 87% from 7,583 in 2010 to 948 in October 2017. All institutions for children with disabilities have been closed and children are living either in residential services, with their families or with foster families.<sup>9</sup>

A number of policy documents since 2014 outline the need for starting a transition process from institutional to community-based care also for adults with disabilities. In practice, however, the process itself was initiated only at the beginning of 2018 with the adoption of an Action plan for the period of 2018-2021 for implementation of the National Strategy for Long-term care<sup>10</sup> (for more information see 1.1.1 and 1.4). The plan was voted after the present research was finalised so its content is not reflected in the report. Nevertheless, sporadic efforts have resulted in an increasing number of community-based services for adults with disabilities as well as some isolated examples of adults (mostly people with lower degrees of impairment) leaving institutions and moving to services in the community.

The overall view shared by all categories of participants in this research while anticipating the official start of the process, ranging from national and local public authorities, practitioners and NGOs, is that the DI of adults will follow the model of the DI of children – that is, building more of the existing types of CBSs rather than moving towards a more individualised approach, such as provision of personal assistance. Civil society organisations and DPOs have raised concern that the DI policy in Bulgaria reproduces the institutional model in the newly-formed "CBSs", simply substituting bigger with smaller institutions keeping people with disabilities isolated from the community, and falling short to obligations enshrined in Article 19 of the Convention on the Rights of persons with disabilities.<sup>11</sup>

<sup>8</sup> For more information, see: <http://topdocumentaryfilms.com/bulgarias-abandoned-children/>.

<sup>9</sup> Bulgaria, Ministry of Labour and Social Policy (2017), [Letter from the Minister of Labour and Social Policy to the Chairperson of the National Assembly \(Писмо на министъра на труда и социалната политика до председателя на 44 НС и до г-н Николай Цонков\)](#), 19 December 2017.

<sup>10</sup> Bulgaria/ Council of Ministers (2018), [План за действие за периода 2018-2021 г. за изпълнение на Националната стратегия за дългосрочна грижа](#), Council Decision 28, 19 January 2018.

<sup>11</sup> See for example: Dimitrova, A. and Parmakova, M. (2015), [Измерване на качеството на социалните услуги в България и Исландия: Сравнителен анализ](#), Sofia, 2015, Cedar Foundation; and Deneva, N. and R. Prtrov (2016), [Живот на воля или по чужда воля! Политиката на т.нар. деинституционализация" \(ДИ\) в България и последиците за правото на независимия живот на хората, с увреждания, които са обект на тази политика](#), Sofia, Center for Independent Living.

## 1.1 Legal and policy framework for deinstitutionalisation

### 1.1.1 National legal and policy framework for deinstitutionalisation

The basis of the deinstitutionalisation process is provided by a number of strategic documents, together with the respective legislative framework as well as regulations with regard to the European Structural and Investment Fund (ESIF) programmes. There are several strategic documents in relation to the DI process. Each of them usually goes with an annual action plan that lists the activities to be accomplished each year, the responsible institutions and the sources of funding needed. In order of their importance to the DI process, the active national strategies are:

- National strategy for long-term care (*Национална стратегия за дългосрочна грижа*)<sup>12</sup> is the strategic document that puts the foundation of the DI process of adults setting the philosophy of community-based services to host people who will leave institutions and at the same time defines measures to prevent institutionalisation. The action plan for its implementation, or the practical instrument that actually put the beginning of the DI process of people with disabilities, was voted on 19 January 2018.<sup>13</sup>
- Action Plan of the Republic of Bulgaria on the Implementation of the UN Convention on the Rights of Persons with Disabilities (2015 – 2020) (*План за действие на Република България за прилагане на Конвенцията за правата на хората с увреждания (2015–2020)*).<sup>14</sup> This is a second document (the first covered the period of 2013-2014) in place after Bulgaria's ratification of the Convention and it outlines all states efforts to implement the Convention in practice. Civil society actors and DPOs criticise the authorities for not implementing the activities and objectives of the first plan in practice but just extending the deadline for the same measures within the term of the second.<sup>15</sup>
- National strategy for persons with disabilities 2016-2020 (*Национална стратегия за хората с увреждания 2016-2020 г.*)<sup>16</sup> and an action plan for its implementation for the period of 2016-2018. This strategic document addresses people with disabilities living in the community trying to offer measures in the field of accessibility of the public environment, non-discrimination, social inclusion, etc. It is one of the measures under the Action plan for the implementation of the CRPD, mentioned above.
- Long-term strategy on the employment of the people with disabilities 2011 – 2020 (*Дългосрочна стратегия за заетост на хората с увреждания 2011 – 2020 г.*)<sup>17</sup> is a specific strategy dealing with the necessary measures to assure long-term employment of people with disabilities. There have been two action plans, for the periods of 2012-2013 and 2014-2015. There is an implementation report for the action plan 2012-2013, which provides an overview of activities, however, no

<sup>12</sup> Bulgaria, Council of Ministers (2014), *National strategy for long-term care (Национална стратегия за дългосрочна грижа)*, Council decision No. 2, 7 January 2014.

<sup>13</sup> Bulgaria, Council of Ministers (2018), *Action plan for the period of 2018-2021 for implementation of the National strategy for long-term care (План за действие за периода 2018-2021 г. за изпълнение на Национална стратегия за дългосрочна грижа)*, Council decision No. 28, 19 January 2018.

<sup>14</sup> Bulgaria, Council of Ministers (2015), *Action Plan of the Republic of Bulgaria on the Implementation of the UN Convention on the Rights of Persons with Disabilities (2015 – 2020) (План за действие на Република България за прилагане на Конвенцията за правата на хората с увреждания (2015–2020))*, Council decision No. 467, 25 June 2015.

<sup>15</sup> Bulgarian Helsinki Committee (2017), *Alternative report about the rights of persons with disabilities in Bulgaria under the UN Convention on the rights of persons with disabilities*, Sofia, May 2017.

<sup>16</sup> Bulgaria, Council of Ministers (2016), *National strategy for persons with disabilities 2016-2020 (Национална стратегия за хората с увреждания 2016-2020 г.)*, Council Decision No. 549, 7 July 2016.

<sup>17</sup> Bulgaria, Council of Ministers (2011), *Long-term strategy on the employment of the people with disabilities 2011 – 2020 (Дългосрочна стратегия за заетост на хората с увреждания 2011 – 2020 г.)*, Council of Ministers Protocol No. 25.2, 29 June 2011.

evaluation of their impact is done and such account of activities is not available for the 2014-2015 action plan.<sup>18</sup> No action plan has been adopted for the following years which in practice means that no activities on this strategy have been running ever since.

- The National social economy concept (*Национална концепция за социална икономика*)<sup>19</sup> and the action plan for its implementation for 2016-2017 are strategic documents that deal with the country's commitment to develop social economy by introducing the concept of social enterprises and organisations, by setting standards that will stimulate the spread of social solidarity and by mapping measures to improve the administrative and legal environment for such activities.
- The National Health Strategy 2020 (*Национална здравна стратегия 2020*)<sup>20</sup> and the action plan for its implementation (until 2020) dedicate two sub-priorities to policies related to people with disabilities – one of them concerns mental health and the other targets generally improving the health of all people with disabilities. The two sections highlight the importance of cross-sector cooperation between the healthcare system and the social system by opening new forms of community services for the people with disabilities.

There are other strategic documents that touch upon issues related to the process of transition from institutional care to living in the community of the people with disabilities worth mentioning. These are the Strategy for Decentralisation 2016-2025 (*Стратегия за децентрализация 2016 – 2025*);<sup>21</sup> the National strategy for reducing poverty and promoting social inclusion 2020 (*Национална стратегия за намаляване на бедността и насърчаване на социалното включване 2020 г.*);<sup>22</sup> the National concept for promoting elderly people's active life (2012-2030) (*Национална концепция за насърчаване на активния живот на възрастните хора (2012-2030 г.)*);<sup>23</sup> etc.

The government's priorities for its mandate of 2017-2021 include one item related to people with disabilities, namely a reform in the disability certification system by transferring it from the healthcare system to the National Social Security Institute (*Национален осигурителен институт*).<sup>24</sup>

The political instability in Bulgaria<sup>25</sup> delayed the DI process and the legislative and strategic documents that were expected to pave the road to transition of adults with disabilities from institutions to community-based living. No new policies have been adopted in 2017. The major document that outlines upcoming activities steps, including a list of institutions, which will be closed first, is the Action plan for the period of 2018-2021 for implementation of the National strategy for long-term care. It was adopted after this research was finalised in mid-2017.

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<sup>18</sup> Bulgaria, Council of Ministers (2014), *Report on the implementation of the Action plan implementing the Long-term strategy on the employment of the people with disabilities 2011 – 2020* (*Доклад за изпълнение на Плана за действие по изпълнение на Дългосрочната стратегия за заетост на хората с увреждания 2011-2020*), Council of Ministers Protocol No. 12.3, 26 March 2014.

<sup>19</sup> Bulgaria, Council of Ministers (2011), National social economy concept (*Национална концепция за социална икономика*), Council Protocol 13.2, 4 April 2012.

<sup>20</sup> Bulgaria, National Assembly (2015), *Национална здравна стратегия 2020* (*National Health Strategy 2020*), National Assembly Decision, 17 December 2015.

<sup>21</sup> Bulgaria, Council of Ministers (2016), *Strategy for Decentralisation 2016-2025* (*Стратегия за децентрализация 2016 – 2025*), Council decision No. 735, 8 September 2016.

<sup>22</sup> Bulgaria, Council of Ministers (2013), *National strategy for reducing poverty and promoting social inclusion 2020* (*Национална стратегия за намаляване на бедността и насърчаване на социалното включване 2020 г.*), Council of Ministers Protocol No. 5.1, 6 February 2013.

<sup>23</sup> Bulgaria, Council of Ministers (2012), *National concept for promoting elderly people's active life (2012-2030)* (*Национална концепция за насърчаване на активния живот на възрастните хора (2012-2030 г.)*), Council of Ministers Protocol No. 24.2, 20 June 2012.

<sup>24</sup> GERB (2017), *Government priorities 2017-2021* (*Приоритети за управление (2017- 2021)*), p. 5.

<sup>25</sup> Bulgaria had six governments between 2013 and 2017.

In May 2017, the new minister of labour and social policy first announced the intention to shift the approach towards more individualised support for people with disabilities by proposing a new Social services act (*Закон за социалните услуги*) to open opportunities for more innovative person-oriented services.<sup>26</sup> By the beginning of 2018, different stakeholders say that there have been consultations in this regard, however no particular outcome has been observed.

By mid-2017, there was also a draft Law on people with disabilities' supported decision-making (*Закон за подкрепено вземане на решения от хора с увреждания*)<sup>27</sup> reforming the guardianship system in Bulgaria in line with Article 12 of the CRPD, which has been under discussion since 2012. To the time of drafting this report the discussion in Parliament is still pending. Research participants' opinion about this law is split between the approval of DPOs and some of the people with disabilities and their family members, and the scepticism of some of the professionals and other family members about how the supported decision making scheme will work in practice.

Overall, national-level stakeholders stress upon the importance of these strategic planning documents for simultaneously declaring the political will for reform and drawing the practical steps for its implementation, including funding.

*"Like any strategic document, especially a national one, undoubtedly a strength is that it is a unifying, inter-institutional, and after all, adopted by the National Assembly, which brings together the efforts of all institutions involved and actually unites and [creates] a common vision of what should be done in future."* (official from a national public authority)

Another strength mentioned by national-level respondents is related to the process of drafting these strategic documents. In their view, all relevant stakeholders take part in the process of policy designing – an understanding that is generally challenged at local level. A significant number of respondents from the case study locality, including representatives of local public authorities, managers and staff at institutional and community-based services, had an opposing view and feel they are not asked about the policies and measures that should be adopted. In particular, social service managers and employees believe that their experience is particularly relevant to help drafting adequate policy measures.

*"I think they don't reach us at all, yet we are those who have the most... we see things more objectively as we are in between – we work with the sick people and simultaneously we receive orders from above [...]. And we see absurd things. [...] these people up there, I have the feeling that they don't have the idea what the real condition of these people is and they put frames that we [...] it is so hard to move in these frames and on the top of that it is all so subjective with us."* (employee of a community-based service)

The reason for this discrepancy is the fact that working groups drafting the strategic and legislative documents are composed by a number of stakeholders that include government bodies, local authorities (not fully represented, but via the National Association of

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<sup>26</sup> Bulgarian National Television (2017), *Social ministry to fulfil the requests of the parents of children with disabilities* ([Социалното министерство ще изпълни исканията на родителите на деца с увреждания](#)), BNT News, 17 May 2017.

<sup>27</sup> Bulgaria, *Draft law on people with disabilities' supported decision-making* ([Закон за подкрепено вземане на решения от хора с увреждания](#)).

Municipalities in Bulgaria<sup>28</sup>) and civil society. These stakeholders are selected by a widely criticised principle of having “nationally representative” organisations, most of which are viewed as dependent on national authorities funding and hence not independent in their function.<sup>29</sup> The local-level stakeholders do not seem to recognise the need of being proactive within the public discussion phase of the legislative and policy-making process. This is probably a function of the often met perception that making decisions is a prerogative of the national authorities and local actors are just executors.

The national, and to a lesser extent local, authorities seem to value more the strategic planning process, which ensures sustainability to the planned activities, while professionals perceive it, together with the legislative process, more as a factor restricting their opportunities to be flexible.

Representatives of national authorities, as well as the members of the local community in the case study locality registered a gap in the strategic planning related to awareness campaigns about improving the public image of people with disabilities. This issue is only covered in Operational Programmes as a requirement for publicity of ESIF-funded projects.

*„And if the government has the solution, or willingness, or resources, it should make a very nice campaign, a serious one, with the good examples – as this place, right, the things that should be more and more visible to the people so that they can see the other side; the good people with disabilities; the good Roma people. This should be massively exposed. But this requires a political backup.“* (member of the local community)

### 1.1.2 Local legal and policy framework for deinstitutionalisation

Local-level authorities have a strictly defined by law role in the deinstitutionalisation process. This role follows the national legislation and comprises of, among others, two levels of strategic planning of social services. The first level, the district level,<sup>30</sup> follows the country’s administrative division where a district combines a number of municipalities and an administrative centre (*областен център*) – usually the district’s largest city. At a district level, district strategies for social service development are developed aiming at coordinating the efforts in the social sphere in a way balancing between different national and local stakeholders unevenly distributed among smaller and bigger localities within the district. Some municipal level officials do not find this level productive as, similarly to the national DI roadmap, the intra-sectoral approach it envisages is not working in practice and therefore these strategies turn to mechanical aggregations of the municipal strategies. Moreover, the district administrations do not have the sufficient capacity and prerogatives to add value to the municipal strategies. The district strategy is prepared on the basis of a demographic and socioeconomic analysis that serves as a background for needs assessment. The analysis and the needs assessment are often integral parts of the strategy.

In addition, every municipality has to draft its own social services development strategy and an annual action plan for its implementation. These are prepared by the local administration’s social department in cooperation with relevant stakeholders and have to be approved by the local parliament – the Municipal Council (*Общински съвет*). Research

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<sup>28</sup> For more information about the National Association of Municipalities in Bulgaria (*Национално сдружение на общините в Република България*), see: [www.namrb.org](http://www.namrb.org).

<sup>29</sup> For more information, see: Alexieva, I., Cohen, E. and Stoychev, V. (2011), *Analysis of the activity of the National council for integration of people with disabilities (Анализ на дейността на Националния съвет за интеграция на хората с увреждания)*, Sofia, Center for independent living.

<sup>30</sup> Under Art. 142 of the Constitution of Bulgaria the district is a unit to conduct regional policy and implement state’s government on the ground assuring balance between the national and local interests.

participants from the local-level administration commented that in practice municipalities with small administration, those that have less population, do not prepare such strategies relying on the district-level ones.

In these strategies, the municipalities plan the social services in accordance with the needs and forecasts of the analysis, including their capacities and the sources of funding. The participants, especially local-level officials, consider these documents particularly important as they act as the locality's evidence-based detailed roadmaps for expanding social services. Local public authorities share the criticism that within the present social system, municipalities do not enjoy security that the Social Assistance Agency (*Агенция за социално подпомагане*) will approve the quality and will set aside state funding for all activities planned at local level. On the role of the Social Assistance Agency see the section below.

## 1.2 Organisation of deinstitutionalisation

The DI process of adults with disabilities was officially initiated some six months after the finalisation of this research so during the conversations with the stakeholders there was a sense of uncertainty in this regard, particularly among professionals in non-managerial positions, who knew that something is being prepared to happen, but still had no concrete information. Others had information about what is being planned based on personal contacts with people at the national level.

The organisation of the process can be viewed in parallel with the organisation of the DI of children and within the framework of the existing legislation. The legislation that regulates the system of social services is the Social Assistance Act (*Закон за социално подпомагане*)<sup>31</sup> and the rules for its implementation.<sup>32</sup> These acts set the frame, in which the Ministry of Labour and Social Policy (MLSP) (*Министерство на труда и социалната политика, МТСП*) – through its subordinated Social Assistance Agency (SAA) (*Агенция за социално подпомагане*) – makes decisions of opening and closing both institutional and community-based services funded by the state as state-delegated activities (*държавно-делегираны дейности*). Furthermore, the Social Assistance Agency exercises control over the service quality in those services. Through its territorial units, the Agency directs people to services, when a need is identified. The Agency also takes active part in the process of drafting national policy and local strategic documents.

Municipalities receive national funding for the provision of the social services identified in their strategic planning instruments (those that are approved by the Social Assistance Agency as state-delegated activity). These can be either managed by the local authorities themselves or subcontracted to non-governmental organisations or private providers. This attaches the municipalities the dual role of being public authorities and at the same time service providers.<sup>33</sup> The process of decentralisation is seen as a positive reform by national-level authorities as it led to a sharp increase in the number of CBSs. DPOs, civil society actors, as well as local authorities, still perceive the system of social services provision as strongly centralised as in practice local authorities have to conform with many financial and quality requirements that do not leave them much freedom to make flexible decisions. Moreover, municipalities do planning and request funding, yet the final decision lies with the national authorities.

<sup>31</sup> Bulgaria, Social Assistance Act (*Закон за социално подпомагане*), 19 May 1998.

<sup>32</sup> Bulgaria, Rules for the implementation of the Social Assistance Act (*Правилник за прилагане на Закона за социално подпомагане*), 1 November 1998.

<sup>33</sup> An example of irregularities related to the functions of local authorities and institutions' management is the subject of a workplace dispute between an institution director and a mayor. Within the case, the Regional Court of Haskovo has to clarify the hierarchy within the system of state-delegated activities at local level. For more information, see: <http://legalacts.justice.bg/Search/GetActContentByActId?actId=U7FBRP3iLDY%3D>.

*"I completely understand the small municipalities, how can they plan anything without knowing if they are going to get state subsidies?" (local official)*

In addition, municipalities offer self-funded social services mostly related to social kitchens and social patronage,<sup>34</sup> preferential parking for people with disabilities, and others.

Research participants are unanimous about the importance of the Ministry of Labour and Social Policy and its Social Assistance Agency as key actors within the DI process. In addition, other national bodies such as the Ministry of Finance, Health Ministry and the Ministry of Labour and Social Policy's Employment Agency were often mentioned as the bodies who should, which they gradually begin to, share the responsibility of the process because of its complexity. Non-governmental organisations were mentioned by the national and local participants as flexible bearers of innovative ideas who, however, often lack administrative capacity to assume roles as service providers themselves.

*"One who works in an NGO gains some sort of an expertise. Beyond one's education. And, based on it, one builds the impression about oneself and about the organisation that they are very good. However, a fact is being missed that they are good in a specific thing on specific scales. Claiming of being really good they compete in a procedure, they win, we speak hypothetically. And at a certain stage it comes up that this is not as easy as it seems." (local level official)*

This general lack of administrative and operational capacity does not allow NGOs to tender for a more significant share of the social services, local officials think. NGOs are also not eligible for obtaining ESIF funding for social services. There are generally only a few private service providers, offering most often palliative care at high fees which makes them unaffordable for most people requiring such support and their families.

At local level, municipal officials responsible for the social sphere are the most important actors, who at the same time plan and deliver social services. The size of the municipality with its specialised human resource and at the same time the political will at local level are mentioned as very important factors within the DI process.

*"The situation is not that "beautiful" with us. The previous local government had no interest at all in the social sphere. Generally, [name] is a tourist site and all local authority efforts were directed there, unfortunately. I told you I have been working in the Municipality since [very recently]. Before that time, there was no person to deal with social activities. As a matter of fact, the only functioning thing several years ago was the institution." (local level official)*

### 1.3 Funding for the deinstitutionalisation process

Social services in Bulgaria can be funded by several different sources – state budget, local budgets, project-based financing within different national or international funding programmes, or self-funded when delivered by private providers.

Social services, being institutional or community-based, are funded by the national budget as state-delegated activities (*държавно делегирани дейности*). The Social Assistance Agency verifies the eligibility for state funding by certifying (registering) those who meet the criteria set in the Social Services Act, the rules for its implementation and other secondary standards defined for each type of service. The later are called 'Method'

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<sup>34</sup> A social services where food from social kitchens is delivered to people with low mobility's homes.

(Методика).<sup>35</sup> The certified (in accordance with the local strategic documents) services receive a set amount of money per user per year. The amounts are fixed every year in a Council of Ministers' (Министерски съвет) decision upon proposal of the Ministry of Finance.

The local authorities can decide to fund social services by their own local budgets. Such financing depends on the yearly approval of the municipal councils thus defined by local-level participants as limited in terms of amount and sustainability. The local authorities can decide to commission both state-delegated and locally-funded services to other providers, yet, the Social Assistance Agency still has to certify them, too.

Both state-delegated and locally-funded social services (institutional and community-based) collect fees from their clients. The amount of the fee for state-funded services is defined in a Council of Ministers' Tariff<sup>36</sup> and represents a share of the clients' personal income (this is usually the person's disability pension but it can include more things, depending on the person's labour experience or other means of income, for example rents). The share depends on the type of service used. The highest fee is charged in institutions for people with intellectual and psychosocial disabilities; and for people with dementia – 80% of the person's 'income'; 50% is the fee in protected houses, centres for accommodation of family type (CAFT) and day-care centres; and 5% - in centres for social rehabilitation and integration. The fees are collected by municipalities, but they cannot use them – the sums return to the state budget. This is another argument of local authorities, DPOs and NGOs who consider the decentralisation process incomplete.

The fees of the locally-funded services are set in the Local Taxes and Fees Act (Закон за местните данъци и такси).<sup>37</sup> It is calculated by summing together the total cost of the service for food, food delivery, bedding, clothes and utility bills. It then divides the total amount to the number of clients, resulting in the fee each individual pays to the service provider.

The project-based funding plays a significant role in piloting innovative services, which can subsequently turn to state-delegated activities. Moreover, the ESIF financing was vital for the realisation of the DI process for children. As local authorities admit:

*"Here I should note that if it was not for the support of these Operational Programmes "Regions in Growth" through the European Regional Development Fund and of the "Human Resources Development" through the European Social Fund, even a large municipality as [name] would not be able to be successful in social service development or in DI. [...] So I would deeply emphasise the enormous help of the two funds in terms of the DI which, I would not say passed, but was initiated and continues. But if it was not for this financial support I am almost sure that it would not happen."* (local level official)

The self-funding is not widely practiced except for a number of private hospices, where the fees are much higher than in other social services.

## 1.4 The status of deinstitutionalisation

The need for change of the institutional approach towards people with disabilities brought the need of general reforms – deinstitutionalisation and reform of the country's system of

<sup>35</sup> For more information, see: [www.asp.government.bg/web/guest/metodiki-i-metodiceski-ukazania](http://www.asp.government.bg/web/guest/metodiki-i-metodiceski-ukazania).

<sup>36</sup> Bulgaria, Council of Ministers, Tariff on the state-funded social service fees (*Тарифа за таксите за социалните услуги, финансирани от държавния бюджет*), 1 January 2003.

<sup>37</sup> Bulgaria, Law on local taxes and fees (*Закон за местните данъци и такси*), 1 January 1998.

social support. Naturally, it was decided to start the DI process with children. The DI process of children started in 2010 and, by 2015, 24 institutions for children with disabilities were closed and some 1,800 children live either in residential community-based services, in their families or in foster families.<sup>38</sup> As of October 2016, some 450 children with disabilities still live in institutions.<sup>39</sup> Nevertheless, the number of children in specialised institutions fell by 82 % between 2010 and mid-2016. By 2020 the DI of children is planned to be completed with an expected proportion of 80 % of the children living in family environment towards 20 % - in residential settlements.<sup>40</sup>

The deinstitutionalisation of children with disabilities intensified similar processes targeting adults with disabilities. As children grow up, the community-based services gradually change to also respond to needs of adults with disabilities and this put them in the position of becoming an alternative to institutional settings.

Currently, long waiting lists for placement in institutions and limited capacity of existing CBSs, has called for increase of community-based services providing residential care for adults with disabilities. The development of new CBSs for adults with disabilities follows the existing model applied within the DI of children, namely only services with set features decided by the Social Assistance Agency are eligible for sustainable state funding. Moreover, a nationally organised DI process for adults was delayed due to the political instability and the lack of determination about the philosophy of the process. Still, the "National strategy for long-term care"<sup>41</sup> sets the foundation of the system of community-based services for adults and the plan for its implementation has put the focus of closing the ten institutions for people with intellectual and psychosocial disabilities that offer worst living conditions by 2021.

This decision is a result of the analysis and expertise of working groups with various stakeholders and a centrally steered mapping of institution for older people and adults with disabilities (*Анализ на състоянието на специализираните институции за възрастни хора и за възрастни хора с увреждания*).<sup>42</sup> By mid-2017 there were signs of will for shifting the policy towards offering more individualised support to adults with disabilities than it was offered within the DI of children. Another step in this direction was the Council of Ministers' decision to set aside additional financing for extending the ESIF-funded programme for provision of assistance to people with disabilities in their homes. The programme which was highly rated by most of the research participants expired in fall-2017.<sup>43</sup> The action plan implementing the Strategy for long-term care seemed to have adopted a balanced approach by both offering the social services similar to those during the DI of children and at the same time by expanding the personal support options.

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<sup>38</sup> Bulgaria, State Agency for Child Protection (2017), [Деинституционализацията на грижата за деца с увреждания – тема на конференцията „Малките стъпки към голямата промяна“](#), Press Release, 26 May 2017.

<sup>39</sup> Bulgaria, Council of Ministers (2016), [Updated plan of action for the implementation of the 'Visiton for the deinstitutionalisation of children in Bulgaria \(Актуализиран план за действие за изпълнение на националната стратегия „Визия за деинституционализацията на децата в Република България“\)](#), Council of Ministers decision No. 859, 13 October 2016.

<sup>40</sup> Bulgaria, Council of Ministers (2016), [Updated plan of action for the implementation of the 'Visiton for the deinstitutionalisation of children in Bulgaria \(Актуализиран план за действие за изпълнение на националната стратегия „Визия за деинституционализацията на децата в Република България“\)](#), Council of Ministers decision No. 859, 13 October 2016.

<sup>41</sup> Bulgaria, Council of Ministers (2014), [National strategy on long-term care](#), in force as of Council decision 2 of 7 January 2014.

<sup>42</sup> Bulgaria, Social Assistance Agency (SAA) (2015), [Анализ на състоянието на специализираните институции за възрастни хора и за възрастни хора с увреждания](#), August 2015. The analysis has been substituted with [Аналитичен доклад на социалните услуги държавно делегирана дейност за пълнолетни лица към 31 май 2017 г.](#)

<sup>43</sup> Bulgaria, Council of Ministers (2017), ['Осигуряват се 15,7 млн. лв. за асистенти на хора с увреждания'](#) Press release, 4 July, 2017.

Certain efforts within the deinstitutionalisation process of adults can be retrospectively outlined. In 2010, the government adopted a concept for DI (unpublished) and a Plan for reforming specialised institutions for adults with disabilities (*План за реформиране на специализираните институции за възрастни хора с увреждания (2010-2011 г.)*)<sup>44</sup>, within which institutions in poor material condition offering low quality of service have been closed. Then in 2012, the MLSP published a draft roadmap for deinstitutionalisation of adults “Vision for Deinstitutionalisation of Adults with Mental Disorders, Mental Retardation and Dementia” (*Национална стратегия „Визия за деинституционализацията на възрастните хора с психични разстройства, умствена изостаналост и деменция“*), a document which did not come into force but was replaced by the “National strategy for long-term care”. Another effort towards DI is the joint Social Assistance Agency and local authorities’ action for closing down professional boarding schools for people with disabilities (*социалните учебно-професионални центрове (СУПЦ)*) – a hybrid form of institution and school.

The natural transition from DI of children with disabilities to the DI of adults between 2014 and 2017 without, however, having a national political framework on how it will be done led to the shared belief that the DI of adults will follow the model of the DI of children. That is building more of the existing types of CBSs rather than turning towards individualised and personalised support. The two approaches popped up within the research as counterpoints. The present model is perceived as reproduction of the institutional model of care in newly created services, while the personalised approach, characterised by the “money follows the person” principle, leads to more support in the community and better independent living outcomes. The second approach is strongly supported by DPOs, as well as other participants from different groups who are familiar with the principles of the CRPD, while the present system of social service provision is supported by local-level social assistance officials and other respondents for various groups who are supporters of the “medical” model of care provision for people with disabilities.

The process of making a political decision on the philosophy of DI of adults has been supported by a number of research works, some of them drawing significant analytical information from the DI of children.

Researchers argue that the DI policy in Bulgaria reproduces the institutional model in the newly-formed “CBSs” failing to assure the main features of living independently by keeping them in isolation and limiting their choice to make decisions.<sup>45</sup> Others outline the challenges in overcoming the consequences of the centralised system of social services’ management – unclear responsibilities of the social work entities, lack of mechanisms for encouragement of public-private partnerships, lack of flexibility of the social services and limited access of NGOs to the sources of funding. They recommend additional efforts to be invested in the quality and effectiveness of the services, as well as in the transparency of the financial reporting of how public funds are being utilised.<sup>46</sup>

Policymakers and all relevant stakeholders can benefit from the analysis of the process of funding the DI of children aiming at bringing evidence of whether the invested funds are

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<sup>44</sup> Unpublished. For more information, see: Bulgaria, General Assembly (2011), [‘Сесия на Народното Събрание 3 June 2011’](#), Transcript, 3 June 2011.

<sup>45</sup> Deneva, N. and R. Petrov (2016), [Живот на воля или по чужда воля! Политиката на т.нар. деинституционализация” \(ДИ\) в България и последиците за правото на независимия живот на хората, с увреждания, които са обект на тази политика](#), Sofia, Center for Independent Living.

<sup>46</sup> Harizanova, N. (2015), *Actual situation of resources in community based social services for people with disabilities in Bulgaria (Актуално състояние на ресурсната осигуреност на социалните услуги, базирани в общността за хора с увреждания в България)*, Е-списание СОЦИАЛНА РАБОТА, 2015, issue 1, year III, pp. 48-64.

effectively utilised to assure sustainability of the process.<sup>47</sup> Some of the conclusions are also relevant for the DI of adults, such as that the urge to quickly complete the process can lead to imbalance of CBSs towards more residential services at the expense of less community support; the practice of transformation of institutions' building to other types of services compromises their quality and at the same time is cost ineffective.

Another research outlines the social service system delegation's disadvantages – the announcement public procurement procedure for subcontracting social services are a subjective decision of the mayor who often has to choose between cutting workplaces and offering higher quality of service when outsourcing. Another deficit is related to the system of control – the municipalities often control only the spending of funds and leave behind the control over the quality of service. The private providers or NGOs delivering social services cannot initiate a procedure for obtaining state funding of a service they offer. Thus, municipality-initiated procedures are tailored to fit a specific applicant who has the necessary facilities and makes the participation of other entities pointless.<sup>48</sup>

A recent report looking specifically at the rights of people with psychosocial and intellectual disabilities living in the institutions and in residential CBSs in Bulgaria<sup>49</sup> concludes that DI, as currently implemented, leads to reproduction of the institutional model in the new type of CBSs, rather than supporting the independency and autonomy of people with disabilities. The CBSs are seen as "last resort" rather than a step towards realising the right to independent living for people with disabilities.

The process of DI of children has been examined by a number of actors looking at achievements and remaining challenges, seeking to inform the new roadmap for deinstitutionalisation of children, adopted in 2015. A report by UNICEF, for example, outlines a number of positive factors throughout the process, such as: clear political determination towards completing the process, successful control over the institutions' entries, and good mechanism of data collection necessary for performing individual assessment of children's needs. The challenges identified by the report, include the insufficient measures towards prevention of the separation of children from their biologic families, the social services for children with disabilities isolate them rather than integrating them in the general systems of education, healthcare and other general services; there is a serious need of training and support of personnel of the new CBSs; and there is no systematic methodology of monitoring the entire social system.<sup>50</sup>

Internationally, Bulgaria was part of a research<sup>51</sup> on the social welfare services for children in 14 countries. The country-specific recommendations stress upon the underdevelopment of mental health care to adequately address the need of children with disabilities; on the need of affordable social housing and the need of improving the quality of healthcare and introduction of interdisciplinary teams to prevent early-age institutionalisation.

Despite those efforts to back the analysis of the DI process of children, the research participants are unanimous that there is a huge need of such an examination of what was done well and what can be improved within the DI of adults with disabilities. They are

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<sup>47</sup> Mulheir, G. et al. (2015), [Прекратяване на институционализацията. Анализ на финансирането на процеса на деинституционализация в България](#), Sofia, LUMOS.

<sup>48</sup> BCNL (2014), [Механизъмът на социалното договаряне в България и европейският опит при предоставянето на социални услуги от външни доставчици](#), Sofia, BCNL.

<sup>49</sup> Petrov, S. et al. (2016), *The not-happening deinstitutionalisation of persons with intellectual impairments in Bulgaria (Неслучващата се деинституционализация на лицата с умствени затруднения в България)*, Sofia, Bulgarian Helsinki Committee.

<sup>50</sup> Rogers, J. (2014), [Деинституционализацията на децата в България – докъде и накъде? Независим преглед на напредъка и предизвикателствата](#), Sofia, UNICEF.

<sup>51</sup> Lara Montero, A. (2016), [Investing in Children's Services: Improving Outcomes](#), European Social Network, Brighton.

convinced that the new action-plan that has initiated the process for adults was not prepared on the basis of such an analysis and there is high probability that mistakes will be repeated.

The detailed local-level research took place in one of Bulgaria's largest cities. The case study municipality has dense population and above country's average economic performance. In terms of stage of DI process in the locality, it represents a mixed picture, typical for other localities in Bulgaria. It took an active part in the DI of children building a relatively good infrastructure of community-based services. Their capacity is occupied with both children and young adults.

There are ongoing efforts to increase the number and type of CBSs in the locality targeting adults with disabilities, especially for people with mental health problems. There are two institutions still operating in full capacity with long waiting lists. There is little choice also in terms of diversity of CBSs, which puts pressure on people's relatives (usually mothers) to quit jobs and take care of their family members with disabilities. The available assistants' service within the national programme "Independent living" („Независим живот") is highly appreciated but criticised for not being sustainable. The locality also offers a low number of small scale self-funded services such as social kitchen, free transportation and parking for people with disabilities.

## 2. UNDERSTANDING OF DEINSTITUTIONALISATION AND INDEPENDENT LIVING

### 2.1 Key terms and concepts

Within the course of the research different levels of understanding of the DI process emerged. Overall, respondents are familiar with the notion of 'deinstitutionalisation' in the context of the already running process of DI of children. In contrast, there were notable differences between groups with regard to understanding of 'independent living', which is not perceived as particularly relevant within the DI of children. Awareness was observed among representatives of DPOs and some NGOs who act as social service providers and among national-level officials who are more familiar with the international instruments dealing with the rights of the people with disabilities.

*"How will people accept and agree to go and live elsewhere, i.e. how they will take their own decision. So far, someone replaced them in making decisions. Sometimes someone else decides for them. Here the focus should be - I alone take my decision. This is a huge challenge, i.e. professionals should support these people to take their decision themselves, not to take the decision for them."* (national level official)

Representatives of the independent living movement believe that DI should enable people to receive the necessary amount of support in the general environment of the community. All other arrangements segregating people from the community, being residential or day-care centers, reproduce the institutional culture and serve to "feed social service providers' financial interests". Representatives of NGOs who are social service providers generally agree but believe that community-based services are a necessary step between the life in the institution and in the community. 'Independent living' then means the opportunity to live among the rest of the people in the community and to have a chance to make decisions, including about where to live. At local level, in contrast, 'independent living' is perceived rather as having own house and a job thus not depending on other people for one's living. DPOs call this "autonomous living".

In addition, national-level authorities feel that service providers lack sufficient understanding of the meaning of independent living, because they lack sufficient training on the spirit of CRPD and DI in particular. This makes them doubtful about the success of the DI process. This point was partially confirmed by the often met opinion among professionals at local level that DI is not possible for all people with disabilities, regardless of age and degree of impairment. There is a general understanding that for older people and people with higher degrees of impairments it is impossible to leave the institution. The grounds for this understanding, however, are the general unavailability and lack of diversity of community-based services. Currently, different needs are met by unified solutions.

Local-level authorities see the DI process within their role to build a new network of services, as decided at national level. There is, it seems, little awareness about the reasons for this shift in service provision.

*"We have given our opinion that if it is decided to take the approach of the Centres for accommodation of family type (CAFTs) (Центрове за настаняване от семеен тип, ЦНСТ), which under the law and the regulations issued by the Ministry of Labour and Social Policy have a maximum capacity of 15 persons we will definitely experience difficulties as the institution for people with intellectual deficiency is with the capacity of 47 persons, right? 48 at the moment. And the other institution has higher capacity of 80 persons. These total approximately to 9 to 10 CAFTS which, as weird as it sounds, is a problem to the municipality [...]." (local-level official)*

Social workers working at local Social Assistance Agency units, who are responsible for evaluating people with disabilities' needs and for directing those to the most suitable means of social assistance, have a specific understanding on the DI process. They see it primarily as a return from institutions to the biological families. This origin of this understanding was impossible to trace. It presumably comes from an internal instruction, probably within the DI of children, saying that people from institutions should first try to "reintegrate" to their biological families and after this proves to be impossible, other options should be sought. Another suggestion tracks this understanding back to the obsolete understandings of the medical approach taught to social workers in universities. A third possible source of this understanding, which is the often found also among first-line workers, originates from the view towards adult people with disabilities as to children. Within the course of the research, a number of social workers and carers kept referring to people at 20-30 years of age as to children.

*"The colleagues do not work for "the big money", nevertheless, they give their best and they treat the clients as their own children. " (local social assistance official)*

Many respondents, primarily those who communicate with people with disabilities on a daily basis, believe that this approach is wrong and impossible to apply in practice as the links between these people and their families is completely destroyed and forcing such reunion would only cause problems to both sides. People with disabilities who have been sent to institution at early age say they do not need parents now when they are adults, and have managed without them so far.

*"Do you know what my clients say, those who have mothers: "Why do I need this person who was not there during my most important years – the first seven years or until I became an adult? Why? Now I work, I have my money, why do I need this person now?" (employee of a community-based service)*

The community members at local level view positively the process of deinstitutionalisation as a liberation of people who have been kept in prison-like facilities.

All respondents are unanimous about the negative consequences of institutional settings on people's lives – they deprive people from their rights to make decisions, even concerning small daily activities; there is no individualised approach towards each person; people are treated there as patients in a hospital in line with the 'medical model' of care.

*„I have been here for five years already. At the beginning, when I came, a big part of the clients were vital and capable to work but they grew old. The newly-accommodated people are absolutely dependent and they require serving - dressing up, bathing, feeding.“* (director of an institution)

Some of the participants at local level, however, find them necessary as they fill-in the gap or any medical services for people with disabilities in the community.

Looking specifically about differences in understanding of what are institutions and community-based services, most of the participants shared a common view. While agreeing that residential community-based services<sup>52</sup> in their current form in Bulgaria – that is Centres for accommodation of family type (CAFTs) and protected houses – provide better living conditions and more personalised care, they are not much different than institutions and are not practically community-based because they offer no support outside their premises. Generally, majority of the respondents classify only non-residential services as community-based. Representatives of DPOs and some social workers, as well as NGO service providers see community-based services as an intermediary period preparing people for independent living in the community by teaching them living and social skills.

Independent living movement supporters go further in saying that all CBSs reproduce the medical model under a new name. People with physical disabilities, who participated in this research, spoke about residential services as places with outnumbered personnel interfering in people's private life; they segregate people with disabilities; and deprive them from the right to choose who to assist them. People with intellectual disabilities, on another hand, perceive residential CBSs as freedom compared to institutions.

*“We had no [financial] resources, no freedom to buy something, to go out, to [...] we stay locked [...] And now we feel free!”* (person with disability)

At local level, there is higher concern about the DI of people with psychosocial disabilities. Participants from all groups expressed fear that the social and healthcare system will not be able to prevent people with mental health problems posing danger to themselves and to the community.

## 2.2 Impact of deinstitutionalisation

At the present stage of DI of adults, it is difficult to speak about its impact on different stakeholders. Nevertheless, the single cases of people leaving institutions to live in group homes or in the community can give an idea about what impact can be expected.

The institutions' staff shares a significant level of insecurity related to the future of their job positions. This is reinforced by the lack of concrete information about the beginning of the process and the institutions that will be closed first (at the time of writing of this report, the Action plan was not published). This insecurity is less relevant for institutions' staff in the case study locality as it is composed of predominantly retired nurses and sanitarians who will not remain out of income. None of them mentioned any possibility of DI training or change of qualification with regard to the forthcoming process.

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<sup>52</sup> As described in the social service legislation.

The local communities are aside of the process of DI, they are not informed of any changes happening at the area they live. Given the continuous practice of keeping people with disabilities invisible in closed settlements during the totalitarian period, this fact unlocks a negative feeling of distrust and fear of the unknown among the local communities. The opening of the residential houses within the DI of children in the locality provoked protests which gradually calmed down when the local officials provided more information about what is being done. In time, participants observe better relations between the neighbours and people with disabilities. Some local community members ask people with disabilities for help when work needs to be done for which they pay them a certain amount of money. In turn, people with disabilities feel useful and use such informal earnings to add to their disability pension. Elderly neighbours happen to come to the group houses to chat and to bring treats to people living there.

Family members of the people with disabilities who have gone through DI do not share that it had any significant impact over their lives. Social assistance officials shared that families were hostile to the information about their relative's possible transition from an institutional to CBS fearing that they would have to take care of him/her. Several people with disabilities, who have left institutions, shared that they attempted to contact their birth families and those, who succeeded, managed to sustain some, although not very close, contacts with them. Parents of people, who moved to live in the community, share a sense of relief that with the introduction of the group houses, their impossibility to take care of their family member does not have to result in his/her living in a closed institution anymore.

The DI process naturally has highest impact on the lives of the people with disabilities themselves. A significant number of them have moved to live in CAFTs or protected houses. Few live in their own homes in the community. There are also some, who have tried to rent their own homes, but were unable to sustain live in the community due to the lack of sufficient support. Still, all participants share their contentment with the change. Despite the certain limitation they still face, ranging from violation of privacy to lack of support to choose what to eat, they emphasised a number of positive changes in their lives. They commented on the significant amount of skills they have learned at their new living arrangements; on the gained self-confidence of those who work, which results in feeling of being useful to society and having additional income; on their emotional wellbeing for both having certain privacy and for being able to communicate with people from the community and not just with people with disabilities, often with higher degrees of impairment, as it was when they lived in institutions.

### 3 ESSENTIAL FEATURES OF THE DEINSTITUTIONALISATION PROCESS

Essential features	Key drivers	Key barriers
<b>3.1 Commitment to deinstitutionalisation</b>	3.1.1 External pressure 3.1.2 Political will 3.1.3 Availability of ESIF funding 3.1.4 Inner conviction in the harm of institutions	3.1.5 Gaps in funding 3.1.6 Lack of sufficient commitment among local-level authorities 3.1.7 Interests to preserve the institutional culture
<b>3.2 Availability of guidance to support the deinstitutionalisation process</b>	3.2.1 NGOs as bearers of innovative practices	3.2.2 Lack of information and experience sharing 3.2.3 Lack of sufficient training and preparation
<b>3.3 Active cooperation between the people involved in the deinstitutionalisation process</b>	3.3.1 Engagement of different ministries 3.3.2 Good cooperation at local level	3.3.3 Poor coordination with healthcare authorities 3.3.4 Practitioners feel excluded from decision-making 3.3.5 Lack of communication with the local communities 3.3.6 The perception of 'being abandoned'
<b>3.4 A change in attitudes towards persons with disabilities</b>	3.4.1 Families prefer CBSs to institutions 3.4.2 Positive examples 3.4.3 Dedication of the social workers	3.4.4 Learned helplessness and overprotection 3.4.5 Resistance towards DI 3.4.6 Negative attitude of the community
<b>3.5 Practical organisation of the deinstitutionalisation process</b>		3.5.1 Urgent need of reform in social sphere bodies, including education 3.5.2 No one leaves residential services 3.5.3 Lack of understanding of the spirit of DI 3.5.4 Lack of diversity of CBSs 3.5.5 Disadvantages of state financing 3.5.6 Lack of sufficient employment and sheltered employment 3.5.7 Deprivation of legal capacity 3.5.8 Significantly lower support once a child turns 3.5.9 Lack of accessible social housing

### 3.1 Commitment to deinstitutionalisation

Commitment to deinstitutionalisation is perceived differently by different groups of participants. While national and local authorities believe that they are doing their best with the support of the European institutions to improve the quality of life of the people with disabilities, others opposed this view. Some of the non-governmental service providers and all representatives of DPOs believe that due to insufficient understanding of the spirit of the CRPD, there is rather a commitment for reproducing the institutional environment in smaller settlements named community-based services. These divergences lead to the phenomenon of perceiving same issues as both drivers and barriers to the DI process. The political instability in Bulgaria during the research period also raised concerns about the sustainability of the commitment towards DI. NGOs add that there is certain scepticism and lack of confidence among decision-makers of different respondent groups about the positive outcome of their efforts. In their view, CRPD is an external, imported factor and there is no inner conviction in it. That is why the DI process in Bulgaria has no genuine leader.

#### 3.1.1 Driver 1 – external pressure

The external pressure has been recognised by most of the participants as an important driver of the DI process in Bulgaria. Firstly, the pressure coming from the EU on the Bulgarian state to implement DI as part of the country's membership obligations, and requirements linked to the granting of EU funding. The other drivers mentioned are the signing and ratification of the CRPD and the European Court of Human Rights cases *Stanev v Bulgaria* and *Stankov v Bulgaria*. These are identified as important incentives for securing political support for the DI process. Last but not least, the huge effect of the BBC documentary "Bulgaria's Abandoned Children"<sup>53</sup> catalysed the process and boosted the commitment of actors at all country's levels.

*"I know what was achieved in Mogilino. Children, which some said would never walk again, they walk. It is my deep conviction that this process should continue."*  
(National-level policy maker)

#### 3.1.2 Driver 2 – political will

National and local authorities commented that political commitment to DI has led to ensuring financing from the European Structural and Investment Funds and as such provides for some security in terms of funds for implementing the process.

National-level stakeholders agree that DI is a political priority in Bulgaria. The political will for its implementation is defined as fundamental and in the words of a national level policymaker *"means in practice that we have been given carte blanche to work."*

This commitment has been challenged by the independent living movement members who believe that a genuine DI process is not a political priority in Bulgaria but rather what is being done simply aims at obtaining ESIF funds for reproduction of the institutional model, or the existing status quo. (See barrier 1 below) As an example, the CAFTs or the non-residential day-care centres do not prevent isolation from the community, on the contrary, they offer a specialised service only for people with disabilities. Hence, the participants characterise the ongoing process as a re-institutionalisation of people with disabilities in a way that violates their rights and does not correspond to the principles DI and independent living.

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<sup>53</sup> For more information, please see: <http://topdocumentaryfilms.com/bulgarias-abandoned-children/>.

*"What we do now is trying to close down our institutions. I hope it will not come time when we will cease our CBSs; I have not heard a nation that has done that. Sincerely, I wish this substitute [of something with something else] would stop, because we do not need simply new houses and buildings, we need a paradigm shift – the way we regard these people to be changed. This is very important."*  
(director of a community-based service)

The political commitment to DI has also resulted into a legislative reform introducing a diversity of social services and allowing for decentralisation of the provision of services. The latter was challenged by independent living movement members who believe that the social system continues to be strictly centralised.

*"This policy is much centralised in practice. Formally, if you look at the law, it is not centralised because of the municipal councils and so on. However, most of the social services are made possible via the so called activities delegated by the state, or if they open a service locally the local authority tries to open it in such a way that it can be funded by the state. And what else can they do, there is no funding, they cannot fund this. That is why I say that it is mega-centralised and this is also demagogic."* (representative of a national disabled persons' organisation)

This can be partially confirmed by the fact that at local level the political commitment to DI is not identified as a driver by local-level authorities and practitioners. Participants from the local level – both officials and front line practitioners – rather outline difficulties in their everyday work resulting from the policy reform.

### 3.1.3 Driver 3 – availability of ESIF financing

The project-based funding of pilot projects within the ESIF Operational programmes is admitted to be of great support not only for setting the standards of social services but also for tailoring the types of services to become state-funded activities. Local authorities, however, argue that while becoming state-delegated activities and thus ensuring sustainability of the projects this shift leads to reduced quality. Participants spoke of less funds which impact on the capacity of the service to maintain good remunerations and being able to afford different specialists (such as psychologists and rehabilitators) but also difficulties in maintaining the buildings and equipment already bought. (See: Barrier 1, section 3.1.5)

### 3.1.4 Driver 4 – inner conviction in the harm of institutions

National-level participants note as a driver to the DI the inner convictions of people working in the social service sector that institutions are harmful to the people living there. Notably, this was not identified as a particular driver for change by other participant groups in this research.

Without having specific knowledge, practitioners, family members and people with disabilities themselves sense the spirit of the CRPD and the paradigm shift it promotes and intuitively apply it. For example, institutions become more open allowing people living there to integrate in the community as much as possible.

Despite that fact, many respondents believe that the institutional principles still exist in the DI policy and practice giving the example of the DI strategy's name – Strategy for long-term care. In their view the notion of care should be totally abandoned.

### 3.1.5 Barrier 1 – gaps in funding

The availability of ESIF financing through the operational programmes (Section 3.1.3) allows for the introduction of innovative practices within the Bulgarian social system. These are often very well accepted by users. There is, however, a gap between the end of the project and the continuation of the service as a state-delegated activity or within another project and during this gap people with disabilities remain with no or limited support when it comes to non-residential services, or the local authorities pay for the residential ones from their own budget, local-level officials say. Moreover, when the project-funded activities become state-delegated, the state financing is usually not sufficient to keep up with the already set standards and their quality drops – their personnel quits due to lower remuneration, the project-built material conditions cannot be sustained.

NGOs add that the access to ESIF funding is not equal for all entities – NGOs cannot apply on an equal basis with municipalities despite being recognised as bearers of innovative practices. Thus, in order to ensure sustainable funding, these NGOs are forced to ‘fit’ their innovative ideas and the support they provide in the limited parameters of state-funded services.

### 3.1.6 Barrier 2 – lack of sufficient commitment among local-level authorities

Local-level authorities lack political commitment to implement the DI process at local level as they see themselves as administrators of national-level decisions. The perception of feeling limited was often met among local-level officials who need to seek national level approval for opening new services and when there is a change in the state funding.

*“Many of the services we opened during the previous programme period became a state-delegated activities as the state [national budget] redistributes the enormous resources, this is how the legislation-set functioning of the state and the municipalities. If they decide, they can continue it [as a state-delegated activity]. The other option we proposed is at least the fees we collect by providing social services, to return [in the local budget] with the obligation, of course, to be used for social services only or in the social sphere.”* (local-level official)

Many participants from different respondent groups raised their voice on the need of a reform introducing a ‘genuine’ decentralisation that allows more flexibility at local level.

### 3.1.7 Barrier 3 – interests to preserve the institutional culture

Independent movement members stressed that the DI process is strongly influenced by vested interests in maintaining the status quo.

*“All we are talking about is policies. And all we are talking about are values, principles and interests. And because the interests are very powerful in the status quo, they are very difficult to break. That’s why I say that only external pressure can help. The interests are outrageously powerful. They are related both to the control and money. Control usually goes with money and vice versa. So the state [...] must necessarily say, “Our policy, the state policy goes into this direction.” Thus, I hope, [name of civil servant] and [name of civil servant] will go themselves. They are unfit to job, because they are unfit to job and fit only for what it is now. We just need a revolution, do you understand? [...] There has not been a situation in world history where such a massive shift of control and restructuring of the power happened without a revolution. This means, what we’re talking about is to take the power from the state and from experts and to give people with disabilities. That’s what it means.”* (representative of a national disabled persons’ organisation)

## 3.2 Availability of guidance to support the deinstitutionalisation process

Guidance and support throughout the entire deinstitutionalisation process were particularly mentioned as important drivers of the process by front-line staff – both directors and employees. As the DI process has not started yet in practice and none of the professionals have received any guidance, naturally they commented on the lack of it.

### 3.2.1 Driver 1 – NGOs as bearers of innovative practices

Both national-level and local-level authorities pointed out that NGOs are a powerful driver for both pushing legislative reforms and for developing and piloting innovative community-based services. Local-level participants added that being bearers of the innovative and the new, combined with their organisational flexibility add much value to the DI process.

The NGOs are not, however, eligible to apply for pilot project funding under ESIF programmes and this, in the view of some local authorities, additionally burdens the local administration to carry the main load of the DI process. Social assistance officials and institutions' managers criticise NGOs managing residential services for 'selecting' their clients thus turning down many people who end in institutions.

### 3.2.2 Barrier 1 – lack of information and experience sharing

Many local-level participants – both local authorities and practitioners commented on the lack of opportunities to share experiences and meet colleagues, identifying this lack of exchange as one of the main barriers to DI. Some of them, try to fill this gap by maintaining personal contacts with colleagues in other localities. Notably, many participants perceived the focus groups organised within this research as trainings and evaluated them as very useful for their every-day work.

Moreover, social services managers do not obtain adequate guidance from national-level officials on how to apply legislation.

*"That is why with the current regulatory framework all my colleagues are unaware what to do. Here is the case of a person coming who is not for us. Nobody explains what you should do. You ask them a concrete question and they answer article X, but I ask specifically for that person, for that individual case, how should I proceed and again I receive an answer – Article X – directly rewritten from the framework which I can read myself." (director of an institution)*

### 3.2.3 Barrier 2 - lack of sufficient training and preparation

Insufficiency of training and preparation of the transition process, was identified as a barrier by most participant, both those who have direct or indirect role in the process.

Institutions and CBSs employees and management shared there is no preparation period, process, or even methodology for the isolated cases of people leaving institutions. This fact was attributed to the very initial stage of the DI of adults with disabilities, still professionals and people with disabilities feel underprepared to handle DI issues. The same applies to social assistance officials and other state institutions' employees who have any relations to people with disabilities, for example Labour offices.

In addition, there is not sufficient training of staff in community-based services. The initially-trained within the DI of children social workers and CBSs support staff have left due to low remuneration, local-level authorities and practitioners say. A representative of a DPO further commented that the mentioned training was not performed effectively so

the social workers had no sufficient and suitable skills when they first met the young people.

*"We have that joke – you teach a woman how to be a mother without having a baby and when the baby comes and she holds it, she forgets everything because you cannot really train with a doll. You cannot train somebody how a person with autism will react, right... beware of this, beware of that. Especially when it comes to Down syndrome.*

*I: You are speaking about the initial training?*

*R: Absolutely! The initial trainings in the empty CAFTs. And at a point they say: 'Alright, now we know.' And when they came... system block, because everyone has his/her own individuality." (representative of a disabled persons organisation)*

Additionally, the insufficient training leads to diverse practices some of which remain in the culture of institutional model of care. Less people agree to work in social services which often forces managers to hire former staff members of the institutions who pass no re-training thus again affirming the presence of the institutional model in the CBSs.

*"Currently, there is a massive problem in recruiting people to work in the small group homes, because nobody wants to work there. It will be the same for the small group homes for adults. You can see this division; I believe my colleague agrees with me, that the qualified people from the institutions were taken to work in those small group homes. With us were left those who cannot cope with the workload. We cannot lie about this." (director of an institution)*

The participants in the peer review meeting of the research findings noted that such trainings should be in line with the principles of DI and the CRPD – a view that was not particularly articulated within the case study research.

Furthermore, there is no supervision and methodological support for social workers. It is present only for the assistants working under the ESIF-funded community support project ending at the fall of 2017. Such supervision could be an active prevention against staff's burn-out and can improve the quality of work and decrease leave rates.

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

#### 3.3.1 Driver 1 – engagement of different ministries

Different Ministries have recognised their role in implementing the CRPD, abandoning the view that the problems of people with disabilities are the sole responsibility of the Ministry of Labour and Social Policy (*Министерство на труда и социалната политика*), national-level authorities believe. For example, the Ministry of Finance has recognised the importance of the DI process realising that institutions are expensive to sustain.

#### 3.3.2 Driver 2 – good cooperation at local level

The good cooperation at local level where the stakeholders know each other and communicate on a daily basis without having to use the formal means for that makes things happen easily. One local-level participant, however, raised concern that such close relations lead to conformity and make divergence of opinions leading to, possibly, better results less likely. Moreover, the local authorities being at the same time social service managers and decision-makers at local level may dominate in processes such as within formal consultation meetings with stakeholders or during supervisory councils.

### 3.3.3 Barrier 1 – poor coordination with healthcare authorities

Local-level authorities, social assistance officials and practitioners stressed as a major barrier – the lack of engagement and coordination with the Ministry of Healthcare (*Министерство на здравеопазването*) in providing health services to people with disabilities in CBSs and in the community. The lack of security about obtaining such services forces many people to prefer institutions – as they will receive the medical care they require without paying additional fees. The same applies, while to a smaller extent, also for CAFTs which also hire medical staff members to assure rehabilitation or psychiatrists. Such health services are often not covered (or not as much as needed) by the health insurance fund.<sup>54</sup> Moreover, social assistance officials criticise health care providers and their emergency units for often refusing to treat people with disabilities.

### 3.3.4 Barrier 2 – practitioners feel excluded from decision-making

Majority of practitioners and some local-level authorities commented that they are not engaged in or consulted in the decision-making process in relation to the DI process. This, in their view, is a barrier that obstructs the process as their practical perspective would add to making strategic decisions that would be realisable in practice. In addition, there is a perception among them that the decision-making officials at ministerial level are detached of the practical work and sometimes their decisions cannot work in practice, or would not provoke the desired effect. National-level officials, however, argue that the policy-making process involves all relevant stakeholders, including NGOs, people with disabilities' organisations and municipalities. The difference in opinions, emerges, most likely, due to the fact that selected representatives only take part in the working groups that prepare different pieces of legal or strategic documents. There is a list of so called "nationally-representative organisations" (*национално-представителни организации*) criticised by DPOs for being bureaucratic. They have exclusive rights to represent the people with disabilities.

*"But I assume that we are not included for the same reason. Formally, we do not have the status of a nationally-representative organisation. There is no other organisation in Bulgaria which works for the independent living the way we do. And most of all, the state does not recognise us."* (representative of a disabled persons' organisation)

The local authorities take part in this process via their association – National Association of the Municipalities of the Republic of Bulgaria (*Национално сдружение на общините в Република България*) which also have representative functions. The social service practitioners are not represented within this process, except for several service providing NGOs. The lack of active vertical communication results in the perception at local level that there are some detached people at central level who develop certain rules and at the other end there are social service management and staff who have to apply these rules without understanding them completely and without having opportunity to receive clarifications.

### 3.3.5 Barrier 3 – lack of communication with the local communities

National authorities, local community members and people with disabilities' family members note the lack of consistent communication with the local communities when it

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<sup>54</sup> Paying health insurance contributions allows for free of charge usage of a set list of health services and procedures. All services, procedures and medical appliances needed should be additionally paid by the patient. The volume of the insurance-covered health services is being negotiated each year and set within a National framework contract for medical activities (*Национален рамков договор за медицински дейности*). For more information, see: [www.nhif.bg/web/guest/1421](http://www.nhif.bg/web/guest/1421).

comes not only to the DI process but to the people with disabilities generally. All groups of participants share their observation of the negative public attitude and stigmatisation of people with disabilities, especially towards people with psychosocial disabilities. However, none of the stakeholders recognise their own responsibility for communicating and raising awareness within the general public.

### 3.3.6 Barrier 4 – the perception of ‘being abandoned’

Family members of people with disabilities shared that they felt abandoned by the government and society as a whole. The insufficiency of social services or assistants’ support leaves the responsibility of providing care to one’s family or close relatives. They are often forced to quit their job and abandon their personal lives. Moreover, the lack of accessibility of the public environment and the lack of understanding they meet when using public services, as well as the discrimination in the community makes them feel alone and abandoned. For example, a mother of a person with epilepsy shared that balneotherapy centres refused to accept her son after he had a fracture because of his diagnosis despite the fact that she would be there as his assistant.

This perception is very strong when having to use general services, in particular healthcare, as doctors often make relatives transport their family member with low mobility to a healthcare centre for examination and relatives have absolutely no means to do this so this person is simply deprived of health services. The situations concerning other services such as employment, education, leisure etc. are similar which further deepens people with disabilities’ isolation and their families’ sense of helplessness.

Another aspect of this perception is that policy making does not involve family members of people with disabilities and those who live in residential social services, DPOs say.

## 3.4 A change in attitudes towards persons with disabilities

### 3.4.1 Driver 1 – families prefer CBSs to institutions

A growing number of people with disabilities and their families recognise the advantages of community-based services and prefer them to institutions. Such a person is Ivan (all names are pseudonyms) who lived in an institution but the institution director convinced his mother and custodian that he would feel much better in the new type of services.

#### **WHAT DI MEANS TO ME: THE STORY OF IVAN**

Ivan left an institution for people with intellectual disabilities. He has not been there all his life – as a child he lived with his family and went to a mainstream school. In time, he could not catch up with the others in learning Bulgarian and English so he moved to a special school where he graduated eighth grade. After graduation, Ivan has to get a profession so his parents push him to go to a specialised professional boarding school where he studies shoemaking. Ivan, however, considers the selection of this profession a mistake because this is not what he wants to do and he has no chance for finding a job. At that time, however, he is not confident enough to choose by himself what to study. His parents are far from supportive but rather overprotective and keep telling him that he is not capable of doing many things.

After graduating, he returns to his family trying to find a job. He tries to work with his father who teaches him to repair audio and video equipment, but this proves to be too difficult for Ivan. As he is not successful in finding a job and after his parents’ divorce, his mother decides to accommodate him at a specialised institution for people with intellectual

disabilities. In order to do so, Ivan is fully deprived of legal capacity and his mother, a person with psychosocial disability herself, becomes his custodian.

He remembers his first days in the institution with having to do physical work that he has never done before. His duties there are to take care of the garden and to sweep up the yard.

Ivan spends 10 years there. He is among the several young men with much lower degree of disability, who are allowed to live more independently and have more responsibilities to take care of the place they live as means to prevent worsening of their condition.

Ivan can leave the institution to go to visit his mother, to attend drawing courses at an artist's atelier in the centre of the city, and to go to a nearby store to buy things if his mother has given him any money. Sometimes he is taken to a vacation at the seaside.

Then he hears about DI and about the possibility for people with milder disabilities to live outside in a new type of social settlements – protected houses. His mother, being his custodian, does not allow him to move out that easy. She is worried about if he is will manage with the life outside but after counselling with the institution director she agrees to let him try.

Ivan moves to the protected house in 2015. There, he feels better, he starts to get to know the city. He learns to cook and he occasionally goes out to work whenever there is work to do – construction brigades call him when there is basic construction work to do, and he clean basements for the neighbours and moves things. Ivan receives a daily wage upon agreement with the employer. He feels well working by having the self-confidence of doing something by himself and not waiting for food and roof to be given to him as charity. He shares he has temporarily left behind painting for discovering other new and interesting things - he has bought himself a DJ set and a computer. Yet, Ivan is still deprived of legal capacity with his mother holding his identity papers – a fact that makes him seek her approval for many things he wants to do.

### 3.4.2 Driver 2 – positive examples

The positive example of people who have left institutions and live independently in the society, show off their achievements through social or mainstream media thus gradually change the perceptions of people with disabilities about their own life and make them look at their future from the perspective of independent living – a fact that was not existing ten years ago.

### 3.4.3 Driver 3 – dedication of the social workers

Most people with disabilities shared that the dedication and the unconditional support of some of their social workers, being in institutions or in community-based services, assured them the security to undergo changes in their lives. These social workers, on the other hand, served as positive example and inspiration for their colleagues.

### 3.4.4 Barrier 1 – learned helplessness and overprotection

Most participants agree that the people with disabilities have learned helplessness and dependency traditionally resulting from the institutional model of care. Moreover, the relatives of those who live with their families take so much care of them and fail to teach them basic skills that practically reproduce the same model at home. The interviewed family members believe that the lack of support for independent living in the community practically segregates and isolates people with disabilities in their homes as institutions

do, therefore, people often prefer institutions and CAFTs for at least being able to provide them with some security and medical care. People with physical disabilities admit that a small number of them have a critical view of the process with the majority focusing on their own personal issues.

*“Many people, I have also been one of them, do not think that people need to earn their living, they have to eat 93 times a month and so on, that this food needs to be cooked, that there is healthy and harmful food. There – the food waits for me three times a day, I don’t think that it should be – everything is ready, they take 70% of my pension and I utilise the remaining 30% about my miserable life and the bearing of responsibility is gone.” (person with disability)*

### 3.4.5 Barrier 2 – resistance towards DI

National-level authorities fear that the resistance towards DI for closing down institutions means job losses will be another barrier to the process.

*“Locally we might meet some resistance in the construction of such services, especially for people with mental illness [and among the very staff of the institutions]. We close their specialised institution, leaving them without work. Surely there will be resistance, as the new services which we intend to build, they will be in the bigger towns, we will be looking for qualified personnel for them. Until now specialised institutions have been located in more isolated locations distant from municipal centers, the local population is part of the personnel in these services, so there is no way that there will be no resistance there.” (national policy maker)*

The in-depth research on the local level, however, showed that the resistance was not related to job losses that much. Firstly, because there was no closure of institutions envisaged in the near future; secondly, institutions’ employees are mainly retired people who, losing their job, will still have the income of their pension; and thirdly, institution employee hope to change their qualification and be able to work in the CBSs to come.

A local-level disabled persons’ organisation argues that the understaffed residential services, together with the social workers’ attitude of care rather than support for people with disabilities results in reproducing life situations within the premises of the services rather than investing efforts to assist and encourage them out in the community.

### 3.4.6 Barrier 3 – negative attitude of the community

National-level stakeholders define as a barrier to the DI process the negative public attitude amplified by media especially when it comes to people with psychosocial disabilities. Yet, at local level, first-line practitioners note the changing attitude once people with disabilities move to the community. They are gradually accepted and form friendships and good neighbourly relations. The fast changing attitudes are even cited as a driver by participants in several localities.

#### **PROMISING PRACTICE: WHEN THE COMMUNITY SUPPORTS PEOPLE WITH DISABILITIES**

The lack of community support and understanding of the problems of people with disabilities was repeatedly cited as a considerable barrier to their full-scale inclusion into community life. This was particularly visible in big cities where people seem less engaged with the well-being of others.

People with disabilities from a Dobrich-based protected house, however, take an active part in the community life, especially when it comes to reading. They started visiting the library years ago accompanied by a social worker. This has open doors for a range of activities in and with the local community. Now many of them go there alone to borrow books. In the house, those who can read, read the books out loud for those who cannot. The library staff is very nice and responsive often organising public reading and educational talks on various topics in cold winter days for them. The staff also invites them to different events as theater performances and exhibitions. The people with intellectual disabilities were invited to take part in a series of speed reading contests organised in the library for the children and young people from the town. The local gallery organises ateliers where the people can get acquainted to different art techniques. The people living in the protected house take part in joint concerts with the local children's choir.

### 3.5 Practical organisation of the deinstitutionalisation process

The stage of the DI of adults with disabilities (See section 1.4) and the political uncertainty pose many questions concerning the approaching process and result in participants' worries about how is it going to run. Moreover, a significant part of them have already took part in the DI of children/children with disabilities and have concerns when speaking about adults. These factors resulted in participants discussing only barriers when speaking about the practical organisation of the process.

#### 3.5.1 Barrier 1 – urgent need of reform in social sphere bodies, including education

Participants across all groups are unanimous about the urgent need of radical reform in the social sphere. First of all reform of the organisation of the Social Assistance Agency and the Employment Agency, and particularly the Agency dedicated to people with disabilities – the Agency for people with disabilities. In their view, both management and employees in these agencies are working based on the medical model of disability and informed by outdated principles. This barrier was not that articulated that clearly during the fieldwork research but was stressed as particularly significant during the peer review meeting.

#### 3.5.2 Barrier 2 – no one leaves residential services

Majority of participants commented that the current availability of CBSs, particularly the residential type, do not fulfil their purpose as an intermediary step in the transition process. They manage to teach a number of independent living and social skills, still people accommodated there do not move ahead to the next stage living on their own with the respective support. The people with disabilities themselves explain this with the lack of security in finding a job, lack of support in the community and lack of sufficient income to be able to afford a number of additional expenses related to their disability – secondary health services such as rehabilitation; accessibility alternations of the home and other necessary possessions such as adapted cars, etc.

Moreover, public environment and general services such as healthcare and employment remain practically inaccessible to people with disabilities – a fact that from one side deprives them from using such services and puts them in a position of dependency and from another side deepens their isolation.

The lack of diversity of social services basically halts the DI process. The lack of support in the community for people who want to live outside the system of residential social services, being institutions or CAFTs, basically forces them to remain in the system of institutional services.

The story of Tanya and Stella show the attempt of two girls who have grown in an institution to live independently in the community and how the lack of support forces them to return to a group house.

#### **WHAT DI MEANS TO ME: THE STORY OF TANYA AND STELLA**

Tanya is 24 years old. She has lived in an institution for children with intellectual disabilities since she was three years old until she was “selected” and moved to the institution for children with physical disabilities where she met her best friend, Stella. Stella has lived in the same institution since she was 3. In time, the girls become best friends and share a room. They find out that they can support each other.

When in 2014 the DI process begins each of them is called to show up before a commission of mostly unknown people. It is composed of some 10 members. Every child goes there to answer questions. The commission has a coordinator who raises her voice loudest of all. After the interviews, the children gather together asking each other where would they go and would they see each other again. The commission asks each of them where they want to go. Tanya chooses to go to her hometown. She also says she wants to be together with Stella. Stella has no preference where to go but she wants to be together with Tanya. The coordinator insists the two girls to be separated. Tanya and an NGO activist speak to her insisting on the two friends remaining together and she finally agrees.

At the second meeting, the girls meet people from their new locality. There is an introductory visit for some of the children but Tanya and Stella are not of them. They only meet their new social workers who tell them about the place they are going to move to but what they hear has nothing to do with what they see afterwards.

By choosing to go to the new town, the girls have no idea where are they going to live – in which neighbourhood; what would the house be; they have no idea when are they leaving.

They move to a protected house where initially they are alone and they feel good. With the new neighbours moving in, Stella is disappointed because she has expected to live with people who can communicate but none of them are able to speak. Stella doesn't feel good as she is given blended food only because her supporting documents say she cannot eat solid food. Tanya raises her voice for her friend, talks to the management and Stella can again eat normally.

The two girls, being among the people with milder disabilities in the house, assist the protected house staff in taking care of other clients, in writing documentation and sometimes in answering the phone. At that time, they have full access to their documentation. That is how they find out that there is another mistake in Stella's documentation – it says that she is deprived of legal capacity.

At that time, the two girls meet their families – Tanya's mother, father and brother live in the town. She goes to visit them, they exchange their phones but they cannot become close. Stella meets her grandmothers and cousins while going to a single visit to her hometown.

The girls' lives change when a person with psychosocial disability comes to live in their protected house. He is aggressive – he throws food at the girls; he tries to push Stella down the stairs several times; and locks her in her room. The girls are constantly harassed and have no privacy, even in their room. These problems make them plan to leave the house and rent a flat. The personnel and Tanya's parents try to convince them not to go there – the personnel say that the girls have everything they need in the protected house, still, do not promise to end their problems with the aggressive person; Tanya's parents are negative fearing that she might come to stay with them.

They move to a flat and live alone for almost two months. There, they have arguments with their landlord as they have to provide access to a common yard via their flat. Stella is weaker and she is the first to want to go back to a residential social service. Tanya does not want to come back and they have an argument. A month after their moving in, they file an application to go back to the protected house, however, despite their places are not taken yet, the director denies to accept them back. They are told that they could be accommodated in a centre for accommodation of family type, a residential service with less free regime than the protected house. They are given a particular date to move and a list of required documents to bring. Among this list, there are a number of medical examination results which the two girls have to get along without any support in terms of assistance, information or transportation. Stella pushes Tanya's wheelchair throughout the town several times in the hot summer days to be able to issue all the documents.

They finally succeed in time and move to the CAFT where they again share a common room. Presently, they are still there. The girls hope they can find jobs. Stella has a distant relationship and she will eventually move to live with her boyfriend someday. Once they complete five years of residing in the town, they will be eligible for applying for municipal housing. Tanya does not exclude this option but Stella is reserved about it scared of what happened when they were alone in their flat. The two girls are aware that they will separate at a certain point of their lives, still they will keep thinking of each other as of sisters.

### 3.5.3 Barrier 3 – lack of understanding of the spirit of DI

National-level participants think that social workers who work directly with people with disabilities lack sufficient knowledge about the CPRD and the philosophy of DI so that they can implement it successfully. DPOs fear that there is lack of awareness of the process that will hinder people's will and preferences will be respected.

Furthermore, the loss of capacity for independent living due to long institutionalisation might prevent the people from standing for their rights.

### 3.5.4 Barrier 4 – lack of diversity of CBSs

There is no sufficient diversity of social services to meet the personal needs of people with disabilities, many participants from different groups at local level say. The system of state funding provides for a centralised decision about what a social service should be so a limited types of services exist. They are not, however, tailored in accordance with people's personal needs. The social assistance legislation was gradually amended to allow more individual approach in evaluating people's needs, still there is no variety of services to meet these needs.

At the same time, local authorities admit that they lack the sufficient human resources of managing even the existing variety of social services. The people with disabilities and their family members insist on the higher importance of personal assistance compared to

existence of a range of social services for both prevention of institutionalisation and in the process of DI.

Personal and home assistants were pointed by most groups of participants by being particularly insufficient and needed. Still, there is a common practice people with disabilities' relatives to be appointed as their assistants receiving salary and social benefits for what they do anyway when the assistants' programmes are not available. Representatives of the independent living movement and some social workers criticise this practice for deepening the isolation of people and reproducing their institutionalisation at home.<sup>55</sup> Most first-line participants agree on the importance of communicating with external to the family persons for the emotional comfort of persons with disability.

Other types of specialised social services needed mentioned by the participants were complex socio-medical services for people with high degree and multiple impairments, hospices and places for people with dementia. The case study locality research revealed shortage of services for people with psychosocial disabilities, as well as flexible types of day-care centres.

### 3.5.5 Barrier 5 – disadvantages of state financing

The system of state-delegated funding which is built to allocate a set amount of money per person does not consider both these persons' specific needs and the needs coming up from the location they live.

*"the whole process deals with a lot of money. What I see as financing now is our ministry of social affairs, altogether with the finance ministry fabricating some sort of standards for the different services. However, within the service itself there are various case-scenarios which are not of anyone's interest. Shouldn't this be thought of? For instance, I am from [town]. We do not need lots of money for heating during the winter, but during the summer, we need money for cooling. Every service comes with a specific, in order to motivate us, they should ask us what we need rather than uniformly distribute the same standards. You have children with disabilities so you get this amount, you have mental patients – this [amount].*

*2: In addition, age [is of prime importance] – a man in his 30s needs certain finances, while a man in his 60s, let's say who has broken a bone – other."*  
(manager of a community-based service)

The state funding, considered the only sustainable way of financing social services, has also the disadvantage of paying for a limited types of services thus forcing people to 'adapt and fit' in existing services, rather than having a system of services responding to diverse needs.

There is no effective quality control of social services provision – this function is not recognised either by municipalities or by the Social Assistance Agency, most participants agree.

In addition, the system of state financing often produces shortages which the municipalities fill with own money. This deprives them from the opportunity to set aside

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<sup>55</sup> Dimitrova, M., Panayotova, K. and Petrov, R. (2016), *Analysis of the assistants' services for people with disabilities through the prism of Art. 19 of UN's CRPD (Анализ на асистентските услуги за хора с увреждания през призмата на чл.19 от Конвенцията на ООН за правата на хората с увреждания)*, Sofia, Centre for independent living.

higher amount from the local budget for own services that can be tailored in accordance with the local specific needs.

*„And what the municipality intended to spend on extending the social patronage service (социален патронаж) by adding paramedics, branches and vehicles, should be spent for additional funding of the CAFTs. There is no way, we are not a big municipality, it's not just us, to be able to additionally fund seven residential services.“ (local-level official)*

### 3.5.6 Barrier 6 – lack of sufficient employment and sheltered employment

The issue of employment of people with disabilities was often mentioned as crucial for the DI and integration back to the society at all levels. There is lack of understanding between national-level decision-makers and all the rest of the groups about the workplace protection of people with disabilities in the labour legislation, including even the beneficiaries. In practice, when an employer hires a person with disabilities, the law provides for safeguards that practically mean that he/she cannot hire the person with disability. This makes employers restrain for hiring such people fearing that if they are not doing their job well, they will still have to keep them at work. Moreover, people with physical disabilities say that the national authorities have not consulted them while developing the programmes for subsidised employment so they are made in a discriminatory way both in terms of job options and, in certain cases, of remuneration. In addition, such jobs are not always permanent thus unreliable for those who have long-term expenses. Still, being the only option for many people to have any type of employment, these enjoy certain enrolment rates.

*“I am angry because we have an Agency for the people with disabilities (Агенция за хората с увреждания), we have an Employment Agency (Агенция по заетостта) and we have no adequate programme. This is terrifying. Our legislations are not so bad, you know, big companies, staff over a certain number, but still nothing happens.“ (director of a community-based service)*

Local administration, local employment authorities and social service managers see the slow development of sheltered employment as a barrier to the DI process. DPOs representatives challenge this view by considering such enterprises as part of the institutional model keeping people with disabilities isolated in their everyday life. In their opinion people with disabilities should obtain support to compete at the open labour market.

### 3.5.7 Barrier 7 – deprivation of legal capacity

The system of deprivation of legal capacity practically deprives people with disabilities of most of their fundamental rights. Often their guardians (in most cases relatives) act in their own interest usually in relation to obtaining people with disabilities' property. Many, especially the independent living movement supporters, see the proposed new legislation that abandons the system of deprivation of legal capacity replacing it with a system of supported decision-making as a chance people with intellectual and psychosocial disabilities to be heard, but others are sceptical about how would it serve its purpose:

*“Let me tell you now, if the deprivation of legal capacity of such sick people with intellectual deficiency is abandoned, people who don't know what they are doing, do you know what happens? One signs [a document]... there are many sneaky people and youngsters: “Come, boy, sign this!” He cannot read and write but the bank comes to ask for its money! ” (family member of a person with disability)*

### **PROMISING PRACTICE: GAINING BACK CONTROL OVER OUR LIVES**

Previously, deprivation of legal capacity was a requirement for people to be accommodated in institutions. So practically, even people with minor disabilities were denied the possibility to make decisions for the purpose of being accommodated in institutions. Their guardians were often family members they hardly knew or officials who were not familiar with their lives.

The Dobrich-based foundation St. Nikolay Chudotvoretz ("Св. Николай Чудотворец") has taken an extraordinary approach towards ensuring autonomy and actual choice and control of six ladies with intellectual disabilities over their lives in a protected house in the locality. In 2015, a 21-year-girl who left an institution within the DI of children initiates before the court the first restoration of legal capacity. She became a full right citizen and this allowed her to find a job and to decide whether she wants to stay in the residential service or continue her life in another direction.

Her example is followed by five more women, the latest of them enjoying her civil rights since February 2017. This change has allowed them to live more independently and to be able to make decisions about their lives. Some of them already have full-time jobs.

This was a legal precedent in Bulgaria which allowed for people with disabilities to re-gain their rights. Many NGOs and DPOs worked towards legislative changes to allow people having back their lives. With the expected abandoning of the system of legal capacity and its replacement with regulation of the supported decision-making, people with disabilities are expected to gradually re-gain control over their lives by learning to make decisions.

*Source: Darik News (2015) За първи път български съд сваля запрещение (Bulgarian court restores legal capacity for the first time), 9 April 2015, <https://dariknews.bg/regioni/dobrich/za-pyrvi-pyt-bylgarski-syd-svalq-zapreshlenie-1417945>*

### 3.5.8 Barrier 8 – significantly lower support once a child turns 18

There is a significant gap between the support available for children with disabilities and that for adults once they turn 18. A lot has been done recently to support families of children with disabilities: financial support, wider variety of social services; healthcare services etc.<sup>56</sup> These benefits and support seize the moment one turns 18 and among the limited possibilities ahead them are the institutions. These factors fill the entrance to institutions and make them difficult to close due to the high application rate and long waiting lists.

### 3.5.9 Barrier 9 – lack of accessible social housing

The participants with physical disabilities outlined the insufficiency of affordable and accessible social housing as a practical barrier to set up their lives outside the system of residential services. People with disabilities apply on an equal basis with other socially vulnerable groups and they have to invest their own money in adapting these houses to

<sup>56</sup> For more information about the recent reforms, please see:

<https://clinica.bg/1311-%D0%9A%D0%B0%D0%BA%D0%B2%D0%B8-%D1%81%D0%B0-%D0%BF%D1%80%D0%BE%D0%BC%D0%B5%D0%BD%D0%B8%D1%82%D0%B5-%D0%BF%D1%80%D0%B8-%D0%BF%D0%BE%D0%BC%D0%BE%D1%89%D0%B8%D1%82%D0%B5-%D0%B7%D0%B0-%D0%B4%D0%B5%D1%86%D0%B0-%D1%81-%D0%A2%D0%95%D0%9B%D0%9A>

be accessible. The local authorities, however, do not identify the need of measures to offer more housing opportunities to people with disabilities.

## 3.6 Cross-cutting issues

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

At national level, the degree of disability is directly linked to the length of institutionalisation and at the same time the long-term institutionalisation is seen as a disabling factor. There is a widespread perception among practitioners, including Social Assistance officials that for people with high degree of impairments and multiple disabilities it is impossible to leave institutions and learn independent living skills. They reason this understanding with the lack of permanent medical care in the community, with their advanced age, with their deeply rooted institutional culture as they have spent their entire life in institutions. Another reason raised is the reluctance of their relatives to take care of them or the fact that they have no relatives at all. A parent of a person with very severe physical disability argues that there are such high degrees of impairment that are not even accepted in institutions.

National-level authorities and IL movement supporters argue that such severe cases can undergo DI, they just need higher level of support. A CBSs manager working challenges the reasons for the above view suggesting that its grounding (the lack of medical services in the community, etc.) are just excuses of a discriminatory belief:

*"Therefore, we must ask ourselves is that the main issue or we continue to truly believe that only a certain proportion of the population are allowed and could have a normal life, and another part are too damaged to live independently." (director of a community-based service)*

There is also a widely spread concern and stigmatisation of people with psychosocial disabilities – DI is considered a challenge among different levels of participants. The community members in the selected locality are particularly negative towards people with such disabilities living in the locality. There are even social service officials who believe that people with psychosocial disabilities are not widely accepted because they tend to stop their treatment, be aggressive and pose threat to themselves and to the others. Therefore, most participants at local level believe that it is better if they stay in a controlled environment.

DPOs share that in practice people with physical and sensory disabilities are more likely to join the Independent living movement while people with psychosocial and intellectual disabilities seem to be under the stricter control of their families and social workers.

Social assistance officials criticised many municipalities for placing together people at different ages and with different types of disabilities where neither staff is prepared to deal with all of them, nor are they able to successfully socialise. There is a similar criticism raised by the National Ombudsman.<sup>57</sup>

### 3.6.2 Impact of age on the deinstitutionalisation process

Similarly to people with high degrees of impairments, people in advanced age are considered almost impossible to deinstitutionalise. Institutions' managers, however,

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<sup>57</sup> Bulgaria, Ombudsman of the Republic of Bulgaria (2016), [Annual Activity Report 2015](#), p. 77.

defend this understanding on the basis of the lack of sufficient alternatives in the community (See also section 3.5.3):

*"The other problem is that those who remain in our institution are at the age of over 60 years old, they have no relatives to support them. We cannot assure support outside."* (director of an institution)

Moreover, many people in advanced age are placed in institutions due to the lack of hospices and palliative care facilities or of the respective support in the community.

The institutionalising environment at home where parents are often overprotective towards their children with disabilities result in lack of life and social skills and as age advances and their parents are no longer able to take care of them, the only option available is accommodation in institution. So institutions traditionally host people in more advanced age, their directors say.

CBSs social workers agree that the age is a significant factor in one's abilities to get used to new things and to gain new skills. This seems particularly true about people who have been accommodated in institutions in their early childhood and have never lived in the community. That is why, many categories of participants – family members, DPOs and social workers – insist on the importance of prevention of institutionalisation proposing early intervention by psychologists at the moment a person with disability is born.

## 4 MEASURES TO ACHIEVE SUCCESSFUL DEINSTITUTIONALISATION

### 4.1 Commitment to deinstitutionalisation

Participants called for overcoming the existing gap between the national and local level policy and decision makers with regard to their commitment to deinstitutionalisation. Local authorities should not only act as executors of decisions made at national level but should take more initiative to act in the spirit of CRPD. This was particularly stressed by national-level officials and disabled persons' organisations say. Independent living movement representatives name this process an 'actual decentralisation' that would come with higher public awareness of the need of DI at local level.

Both levels of governance agree that DI is responsibility of the national authorities in terms of adopting the right approach but in coordination with the local actors. This decision-making process should involve all stakeholders, including families of people with disabilities and people with disabilities, including those living in residential social services. At local level, the responsibilities are to implement this process with the methodological support of the central authorities – a feature that is presently defined as missing.

There is also need of awareness among legislators about the urgent need of abandoning the system of deprivation of legal capacity. This issue should get higher priority at the National Assembly.

Furthermore, all groups of respondents are unanimous that despite its importance, DI is a very long and complicated process and it should not be rushed to fit certain strategic or financial framework.

*"[...] what they have done, the developed European countries, they have done in a period of 40-50 years. We are asked to do it in 3-5-10 years? You cannot do it for this amount of time and do it well. If we need to close down the institutions, we will shut them down, but the problems will remain. The people are not going to live much better. We want to do it more smoothly, but for it to be a really genuine process."<sup>58</sup> (national policy maker)*

National authorities, DPOs and local community members identified the need of awareness raising campaigns targeted at different actors in the process and aiming at popularising the spirit of the CRPD.

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

Guidance and support was defined as particularly important for the DI process. National authorities recognise the need of additional training of the spirit of CRPD and the principles of independent living to practitioners so that they can implement the process with no difficulties. At local level, both local authorities and service personnel outlined the need of guidance in the practical implementation, i.e. how to treat individual cases, how to apply new law provisions, etc. Still, there is a sense of the need of practical written instructions rather than education in the spirit of the process and applying it case by case.

*"In conversations and in instruction letters we sense common thinking, they understand the problems. Still, in Bulgaria, we are somehow used to working with laws, with decrees. We will cooperate if someone orders us to but if it comes to*

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<sup>59</sup> An example can be found at: [www.marginalia.bg/analizi/chovekat-pod-zapreshenie-e-nevidim-i-bezglasen/](http://www.marginalia.bg/analizi/chovekat-pod-zapreshenie-e-nevidim-i-bezglasen/).

*initiative and creativity, it is very difficult. But obviously when it comes to precisely the Health Ministry, it should be acted at the highest level. (local social assistance official)*

The issue of re-training of personnel was again recognised as important at national level, by DPOs and by people with physical disabilities engaged with self-advocacy. Social workers themselves, despite admitting the need of additional qualification, do not see a need for a change of the perspective of their work. Re-training in the spirit of CRPD was mentioned only at the peer review meeting.

Having pilot projects under the ESIF financing was defined determinant to the implementation of the DI of children and these are expected to play an important role within the DI of adults. The guidelines for projects' implementation will impact and shape the practical implementation of the DI process in Bulgaria. The problems outlined are related to the time gap between their end and the point of their becoming state-delegated activities, as well as to the financial insufficiency of the state-delegated budgets to sustain the quality standards set within the pilot phase. Participants called to national-level authorities' to engage more with the finance ministry and argue about the importance of the sufficient national funding to the success of the DI process.

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

Several active cooperation measures already emerged, such as the need of closer vertical cooperation between national and local level policy-makers and practitioners and horizontally between different ministries to assure the successful implementation of the process.

In addition, DPOs and local authorities proposed more active inclusion of other sectors such as housing, healthcare and employment in the DI process as all recognise their role in providing a quality of life for the people with disabilities in the community that will both encourage more people to leave institutions and will at the same time act as a prevention to institutionalisation.

National-level officials call upon practitioners and local authorities to be more active in their contacts with the national authorities when public consultations or drafting of legislation takes place as social service management and staff should not be imposed rules and legislation they do not understand.

Some participants, especially DPOs, note the need of involving families of people with disabilities and those living in residential social services, both institutional and CAFTs/protected houses, in the decision-making process.

All categories of participants recognise the significance of involvement of wider society and local communities in the process, still none of them recognises it as their own responsibility. Local authorities and part of the community believe that the media should act responsively when dealing with social issues as they have the responsibility of shaping the public opinion. The local community at the selected locality, however, believes that changing the public attitude should be a government-initiated national policy:

*„ So I think that with a slight 'push' by the government and with some [...] if I had the power, I would go to the film industry and the theatre industry and I would say them: 'Dudes, I need your help! We want a series – a disabled person, two Roma in another series, I want a Roma starring, I want things like that... I want people*

*to see that there are normal people among them. And I want them to become examples to follow.” (member of the local community)*

All groups of respondents agree on the primary importance of the prevention of institutionalisation to the success of the DI process. Among the most often mentioned prevention measures were information and psychological support of parents of new-born children with disabilities and support measures for people with disabilities who live in their homes.

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

Most participants agreed on the importance of more and more people with disabilities living in the community thus changing the public perception and acceptance towards themselves. The personal stories in the selected locality affirmed this understanding. Fear of the unknown and the helplessness the community feels in the presence of people with disabilities quickly changes into positive and friendly attitude.

*“If you ask me – keeping population informed that those are people with a health problem, they need special care and attitude, but they are no different, to an extent, from all of us. Because people are afraid of the thought that psychic patients will come to live beside them. This is what we see, regularly, in media as well... And everywhere, they come and say ‘He lives on our street, he is dangerous!’ But, de facto, when he takes his medicine regularly, and uses some service in the family environment, he is as dangerous as they try to depict. So information among people is a huge factor; one of the main factors to stimulate DI.” (local social assistance official)*

The attitude of the practitioners was mentioned by national-level stakeholders as an important factor to successful DI process. The people responsible for policy implementation at local level and especially service providers and the local branches of the Social Assistance Agency (*Агенция за социално подпомагане*) need to be trained to gain sufficient knowledge and competence in the new principles of social work in accordance to the CRPD. A representative of a DPO adds the need of rethinking the model of social work science taught at the university dating back from totalitarian times and offering conservative and outdated approach. The social services staff themselves admit they feel uncertain in many situations and need additional qualification, although they could not specify which their weak areas are.

Institutions’ directors and social assistance officials stress upon the need of change on families’ attitudes towards taking responsibility for their relatives with disabilities rather than sending them to institutions. DPOs and people with disabilities see the change in families from the IL point of view speaking about the need of change of the tradition of overprotection.

*“The social skills are formed in family environment – when mommy allows her child with disabilities to fight the other small punks in the street – this is called social environment. When mommy keeps you closed and waters you by the window, it is normal for you to have none, to say: “Look, what are these?” and not to even know that these are children and they are of your age. When an illiterate parent is growing a healthy child, even a marginalised one in this country, it becomes an illiterate small idiot, what else can come out? Afterwards, it does not matter in what environment you put it.” (employee of a community-based service)*

People with physical disabilities and some family members believe that people with disabilities themselves should be more active in pursuing their rights and initiating change

both at policy level and in terms of public perception about them. They should be supported by measures and programmes teaching independent living and overcoming learned dependency, DPOs say.

#### **PROMISING PRACTICE: EMPOWERING YOUNG PEOPLE WITH INTELLECTUAL DISABILITIES**

Association „Parallel World“ (*Сдружение „Паралелен свят“*) is a Plovdiv-based organisation working with young people with disabilities. It runs a project that aims at capacity building of young people with intellectual disabilities in self-advocacy by developing their skills of autonomous action in approaching public institutions and playing more significant role in the process of making decisions about their lives. The association simultaneously works with young people’s parents to expand the level of understanding of the principles of independent living and rights protection. This initiative is particularly important in this city where few organisations of people with disabilities exist and at the same time for its targeting of people with intellectual disabilities that are usually less active and less likely to engage with self-advocacy. At the same time, the initiative adds value to increasing the public awareness about the needs of people with intellectual disabilities and raises public authorities’ sensitiveness about their problems.

Source: [www.paralelensviat.com/](http://www.paralelensviat.com/)

The local community members and national-level public officials recognised the need of a wide awareness campaign, involving media, artists and public figures that should work towards changing the attitude towards people with disabilities and promoting acceptance.

#### **4.5 Practical organisation of the deinstitutionalisation process**

Almost all participants believe that the social system should change in order to have successful DI process. Two types of changes could be distinguished among the various opinions. Participants close to the views of the independent living movement believe that the current system of funding of social services should be abandoned and instead of spending a significant amount of money in reproducing institutional-by-spirit services, the government should support persons with disabilities in four main areas: personal assistance; education and qualification; accessible social housing (with no staff present to replace residential services) and accessibility of the public environment. The principle of segregating people with disabilities in new forms of services should be replaced by person-centred system where one should first have their needs evaluated and they will receive the required support into an environment of their choice.

The other group of participants, consisting of social assistance officials, service providing NGOs, social services staff and people with intellectual disabilities, believe that the present system of social services should be expanded by adding more and more diverse services to meet all the possible options of personal needs. Service directors think that CBSs should be as flexible as possible to offer individualised support to their clients. Social assistance officials add that the services should be more evenly territorially distributed so that people in smaller and distant localities should have access to them.

Both groups consider really important the introduction of the ‘money follows the person’ principle of funding - a factor that will significantly improve the quality of support people obtain now.

Moreover, there should be strict quality control of what public money are spent for.

There is a third group of participants from almost all categories at local level who does not have a vision about the philosophy of the DI process but rather see themselves agents implementing what is decided at central level. This group seemed less concerned about realising the right to live independently for people with disabilities and rather focuses on their narrow duties.

Social assistance officials and institutions' directors believe that institutions should not be closed as there are people who need them. Directors think that they should offer better living conditions and more open regime to socialise people living there as much as possible. Regardless of the DI process, the institutions' management should be more active in ensuring people with disabilities live in an environment – as close as possible to the one in the community.

#### **WHAT DI MEANS TO ME: THE STORY OF STANISLAV**

Stanislav grew up without parents – his mother died and he never knew who his father was. As a child, he goes to a mainstream school in the village he lives but he hardly catches up with others. Nobody pays attention at his problems at school so he moves to a special school for people with disabilities after fourth grade. When he is about to graduate, social workers come to him and offer him to go to a specialised professional boarding school. He can choose between two such schools in two different cities. He chooses the one closer to his hometown and moves there to study the profession of a painter. After the three-year qualification he tries to find a job but he fails. He has no home or any other support so he goes to an institution for adults with intellectual disabilities where he can have food and a roof. He spends 15 years there – from 2002 to 2016.

Stanislav does not feel good there. He has to live with many different people – old, young, different conditions that he has to conform to. He is lucky to share a room with four more people with lower degree of disability and enjoys a more liberal regime, still he does not feel well. He feels isolated from his friends outside. He is ashamed to invite them to visit as they see the other people in the institution and do not want to visit him anymore. He feels lonely as the other people are gradually less capable of having a conversation. When he hears that new types of services, protected houses, are being open, he asks to leave the institution. He goes to the director saying that he feels he does not belong there anymore. He does not want his life to pass there. The director understands and helps him to do the necessary steps to move out to a protected house.

Stanislav can freely go in and out of the institution so he goes to visit the new protected house and ask what he has to do to apply for living there. He prepares the documents needed alone and applies at the Social Protection Directorate. He has to wait for a month his application to be approved. This seems to be a long month for him.

He moves to the protected house on 8 June. He likes it a lot there. He feels free and likes the house very much. He has skills in construction works and is often employed. Now he has his own income and affords to buy different things – a cell phone, things he likes to eat, nice clothes. Stanislav is thankful for the chance to live there. He has no plans to leave the protected house and have his own home.

All groups of participants are convinced that a radical reform in the Social Assistance Agency and its territorial units is needed, in order to move away from outdated principles of work based on the medical model. It should become a decentralised structure and work towards regaining the social prestige of the social workers. They, in turn, are taught these

outdated principles at the university where social science teaching should be urgently updated to seize to produce social workers who need retraining.

Employment was repeatedly named as maybe the most important factor for successful reintegration to the society both for assuring financial resources to lead a normal life and social contacts and perception of being useful. Employment measures proposed by participants were of two general types – social service professionals considered social employment as most suitable for people who have been in institutions. On the other hand, independent living supporters – people with disabilities and DPOs – believe that equal participation at the labour market will make people with disabilities compatible workforce and will integrate them to the society in the best possible way.

The successful deinstitutionalisation requires also a reform in the system of deprivation of legal capacity, most participants think. Few of them, however, mainly those engaged in developing the proposed (not voted yet) system of supported decision-making have concrete idea what can substitute the present one. There is a debate in the society about what safeguards can be proposed against abuse of potential advisory circle members. Family members of people with disabilities deprived of legal capacity oppose this reform believing that they are the only people to best protect their relatives despite the numerous evidence of misuse of property available at national level.<sup>59</sup>

Most of participants stressed the importance of prevention to institutionalisation in terms of psychological work and support of families to gradually decrease the need of institutions. A DPO from the case study locality mentions the need of early intervention at maternity hospitals where a significant number of children with disabilities are abandoned.

The social assistance directorates and some social service staff and management said social sphere workers should receive higher remuneration so that quality personnel can be attracted to the social sphere. Other practitioners argue that the quality social workers are dedicated to their work and it is more like a cause to them than just a job.

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<sup>59</sup> An example can be found at: [www.marginalia.bg/analizi/chovekat-pod-zapreshlenie-e-nevidim-i-bezglasen/](http://www.marginalia.bg/analizi/chovekat-pod-zapreshlenie-e-nevidim-i-bezglasen/).

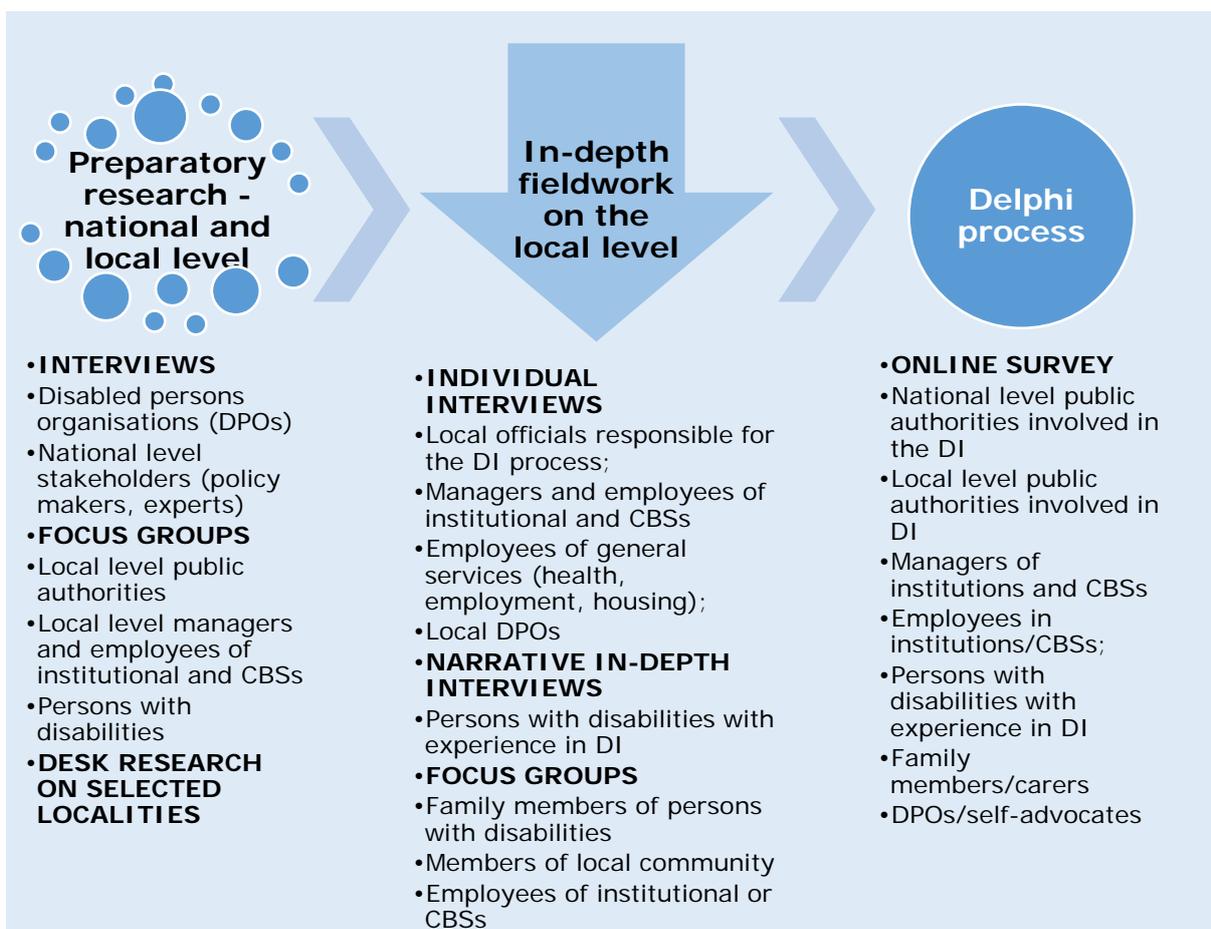
## ANNEX: RESEARCH METHODOLOGY

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>60</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>60</sup> Hsu, Chia-Chien and Sanford, A., Brian (2007), [The Delphi Technique: Making Sense of Consensus](#), Practical Assessment, Research and Evaluation, No. 10/12; Cuhls, K. (2005) [The Delphi Method](#), Fraunhofer Institute for System and Innovation Research ISI.