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Dear Ms Nikolova,

REQUEST FOR IMMEDIATE SUSPENSION: Call for Proposals BG16RFOP001-5.002 "Support for the deinstitutionalisation of services for adults and people with disabilities" under Priority Axis 5 (Regional social infrastructure)

- 1. The following organisations submit this request to the Bulgarian Government to request an immediate suspension of the implementation of projects under the grant scheme BG16RFOP001-5.002, funded by the European Regional Development Fund:
- 2. The **European Network on Independent Living** ("ENIL"). ENIL is a user-led, cross-disability rights civil society organisation, with members in 47 countries across Europe. ENIL represents the disability movement for human rights and social inclusion based on solidarity, peer support, deinstitutionalisation, democracy, self-representation, cross-disability and self-determination. For more information please visit: www.enil.eu.
- 3. The **Centre for Independent Living Sofia** ("CIL Sofia"). CIL Sofia is a disability rights organisation set up in 1995 in Sofia, Bulgaria. It is run and controlled by disabled people who want to live independently in the community, to make choices by themselves and participate in society as all citizens do. CIL Sofia advocates for public policies that will enable all disabled people regardless of the impairment to be included in society, to develop and reach their full potential through access to education, employment, family life, etc. The main areas of activity cover deinstitutionalisation through housing measures, availability of personal assistance, technical aids, accessible environment and peer support. For more information, please visit: www.cil.bg
- 4. Validity Foundation (formerly known as Mental Disability Advocacy Centre / "MDAC") is an international human rights organisation which uses the law to secure equality, inclusion and justice for people with mental disabilities worldwide. MDAC's vision is a world of equality where emotional, mental and learning differences are valued equally; where the inherent autonomy and dignity of each person is fully respected; and where human rights are realised for all persons without discrimination of any form. For more information, please visit www.validity.ngo

Background

- 5. In March 2018, a Call for Proposals was published under the procedure "Support for deinstitutionalization of social services for older people and people with disabilities" (BG16RFOP001-5.002). The procedure aims to facilitate the process of deinstitutionalisation by securing "suitable infrastructure, supporting the provision of new quality services for people with disabilities and older people". It is co-financed by the European Regional Development Fund (ERDF), through the Operational Programme 'Regions in Growth', with 17 981 053,14 EUR, which represents 85% of the total funding. This funding will be used for the building, renovation, furnishing and equipment of 6 day-care centres and 68 care homes for older people and people with disabilities, including people with mental health problems, intellectual disabilities and people with dementia. The deadline for the implementation of the infrastructural projects is 2 years after their start.
- 6. A total of 29 municipalities have been selected for the development of the new services (day-care centres and care homes), with the number of services ranging between 1 and 9 per municipality.

Relevant legal standards

- 7. Under the priority objective "Promoting social inclusion, combating poverty and any discrimination", the European Regional Development Fund (ERDF) Regulation contains the investment priority on the "transition from institutional to community-based services". The Regulation defines community-based services as "all forms of in-home, family-based, residential and other community services which support the right of all persons to live in the community, with an equality of choices, and which seek to prevent isolation or segregation from the community". To benefit from this financing, Member States must comply with ex ante conditionalities, set down in the Common Provisions Regulation.³ Of particular relevance are conditionalities related to promoting social inclusion, combating poverty and any discrimination; anti-discrimination; and disability (i.e. the application of the UN Convention on the Rights of Persons with Disabilities). Further guidance on the contribution of the European Structural and Investment (ESI) Funds to deinstitutionalisation can be found in the Common European Guidelines on the Transition from Institutional to Community-based Care⁴, published by the European Expert Group on the Transition from Institutional to Community-based Care in November 2012 and endorsed by the European Commission.
- 8. The Charter of Fundamental Rights of the European Union guarantees the protection of fundamental rights for citizens and residents of EU Member States, including respect for human dignity (Article 1), private and family life (Article 7), equality (Article 20), non-discrimination (Article 21), and the integration of persons with disabilities (Article 26).

¹ Ministry of Regional Development and Public Works (2018) *Nasoki za kandidatstvane* [Guidelines for Applicants, procedure BG16RFOP001-5.002 'Support for deinstitutionalization of social services for older people and people with disabilities'].

² EEG (2014) Toolkit on the Use of EU Funds for the Transition from Institutional to Community-based Care, Revised edition, p. 25.

³ Article 19 and Annex XI, Part 1 (Thematic ex-ante conditionalities) of the Regulation (EU) No 1303/2013 of the European Parliament and of the Council.

⁴ 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. Available at: https://deinstitutionalisation.com/eeg-publications/.

- 9. Bulgaria is a State party to the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD), which it ratified in 2012. As a regional integration organisation, the EU also became a party to the treaty by way of confirmation in 2010. Ratification or confirmation of the treaty creates binding obligations under international law on parties to promote, protect and fulfil the human rights of all persons with disabilities, including the right to independent living and inclusion in the community (Article 19), the right to equal recognition before the law (Article 12) and the right to the equal protection and equal benefit of the law without discrimination (Article 5).
- 10. Pursuant to Article 19 CRPD, persons with disabilities have the right to live independently and be included in the community, with choices equal to others. States must ensure that persons with disabilities can "choose their place of residence and where and with whom they live" and that they are "not obliged to live in a particular living arrangement". This requires "access to a range or in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community." It also requires access to mainstream services and facilities, which should be available and "responsive to their needs". To ensure that services are responsive to individual needs, a thorough individual needs assessment is required, with the goal of facilitating disabled people's social inclusion and participation in society. As part of this process, it is important to map out individual wishes and requirements of all those in institutional settings (including small group homes), and invest into different community-based alternatives to meet everyone's needs and requirements.
- 11. The General Comment No. 5 on Article 19 CRPD⁵, adopted by the Committee on the Rights of Persons with Disabilities (CRPD Committee) in 2017, sets out the defining characteristics of institutional care settings. These include: "obligatory sharing of assistants with others and no or limited influence over whom one has to accept assistance from; isolation and segregation from independent life within the community; lack of control over day-to-day decisions; lack of choice over whom to live with; rigidity of routine irrespective of personal will and preferences; identical activities in the same place for a group of persons under a certain authority; a paternalistic approach in service provision; supervision of living arrangements; and usually also a disproportion in the number of persons with disabilities living in the same environment."
- 12. In the Concluding Observations on the initial report of Bulgaria on the implementation of the CRPD, published on 22 October 2018, the CRPD Committee expressed deep concerns about the Government's strategy to transfer residents from large institutions to small group homes, contrary to Article 19 CRPD.⁶ It asked the Government to ensure that all persons with disabilities, including those "in small community-based group homes" have the right to live independently in the community, to allocate resources for individualised support services, such as personal assistance, and to ensure that EU Funds are used to "promote the inclusion of persons with disabilities in society".⁷
- 13. In the submitting organisations' view, the projects approved for funding under grant scheme BG16RFOP001-5.002 do not comply with these binding European and international standards due to the reasons set out below.

⁵ Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para 16(c).

⁶ Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Bulgaria, CRPD/C/BGR/CO/1, 22 October 2018, para 39.

⁷ Ibid, para 40.

Specific issues with the grant scheme BG16RFOP001-5.002

- 14. The process of "deinstitutionalisation of social services for older people and people with disabilities" is dominated by a narrow focus on building residential care facilities (also referred to as 'care homes' or 'small group homes') as alternatives to large institutions. Rather than being able to decide where, with whom and how to live, which is one of the core elements of Article 19, people with disabilities will simply be moved from large institutions into smaller facilities. For example, in the municipality of Dryanovo (population 7,968), 7 care homes will be built to accommodate 100 residents of an institution for women with disabilities, in groups of 12. While physical conditions in the care homes will undoubtedly be better than in the large institution, the segregation and isolation of these women, in a small town, will continue. As explained in the General Comment No. 5, "all support services must be designed to support living within the community, preventing isolation and segregation from others, [...] therefore, any institutional form of support services which segregates and limits personal autonomy is not permitted by article 19 (b)."
- 15. As stated in the Action Plan 2018-2021 to the National Strategy for Long-term Care, the rationale for moving people from large institutions into smaller facilities is that most people living in institutions do not have families to look after them and therefore need residential care. While it may be true that many people in institutions do not have family support, it is important to stress that they do have different support needs and preferences and one solution will not be suitable for all. Following the requirements of Article 19 CRPD, mapping of individual needs is a crucial element, and investments should be tailored to respond to the informed choices and requirements of individuals leaving the large institutions. There are other ways to organise the provision of housing and support, allowing for more choice and control of people with disabilities and older people and genuine inclusion and participation in the community, in line with the CRPD and the Charter. For example, the Common European Guidelines stress that it is important to ensure that the provision of housing and support is separated, that housing is dispersed in the community and that it is of the type and size the majority of the population lives in. The General Comment No. 5 highlights the importance of individualised support, including personal assistance, which should be made available to all people with disabilities, regardless of their impairment.
- 16. A recent evaluation of deinstitutionalisation of services for children with disabilities in Bulgaria, in the period 2007 2014⁹ during which hundreds of group homes were built to accommodate children from large institutions has shown that the **majority of the children with disabilities placed in group homes continue to live in isolation**, with no opportunities to learn and develop, spending most of their time in the setting a situation similar to that in traditional institutions.
- 17. Regardless of the fact that this grant scheme will be used to fund infrastructure, and that there is no information about the type of support and other services that residents will receive, it is clear that the care homes will not facilitate the right of persons with disabilities to live independently and to be included in the community. The

⁸ Committee on the Rights of Persons with Disabilities, General Comment No. 5 (2017) on living independently and being included in the community, CRPD/C/GC/5, 27 October 2017, para 30.

⁹ Lumos (2015) Ending Institutionalisation: An Assessment of the Outcomes for Children and Young People in Bulgaria Who Moved from Institutions to the Community. Available at: https://lumos.contentfiles.net/media/documents/document/2017/02/Bulgarian Outcomes Report ENG.pdf.

infrastructure development should include investments in accessible mainstream environment, incl. housing, and should be closely linked to investments in human capital, in order to provide the necessary services and put in place the conditions to deliver quality community-based services, in line with Article 19 CRPD. This link is completely missing. Moreover, there is no doubt that the new settings will retain a number of institutional care characteristics, such as "a disproportion in the number of persons with disabilities living in the same environment and isolation and segregation from independent life in the community".

18. It can be concluded that this grant scheme is not directed at the elimination of large institutions and institutional culture, but rather at the maintenance of the system that fails to provide individualised support and uses the 'one size fits all' approach. The grant scheme fails to advance the inclusion of people with disabilities in their communities and instead of contributing to a shift from institutional care to community-based support, will result in the trans-institutionalisation of residents. Should this grant scheme proceed, we believe that it will run contrary to Bulgaria's obligations under international and EU law, enshrined also in ESI Funds Regulations.

Requests to the Government

- 19. We urge the Bulgarian Government **to immediately suspend** the grant scheme BG16RFOP001-5.002.
- 20. We ask the Government to ensure that the new Call for Proposals under the procedure "Support for deinstitutionalisation of social services for older people and people with disabilities" is in line with Article 19 CRPD, specifically that any new infrastructure facilitates the right of persons with disabilities to decide where and with whom to live, and promotes their inclusion and participation in society.
- 21. We further urge the Government to immediately establish a genuine and effective process for engagement with civil society organisations, including those advocating for independent living and human rights of persons with disabilities, and to implement and monitor a CRPD-compliant deinstitutionalisation process that actively takes into account their views and recommendations at every stage.

Yours sincerely,

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