EUROPEAN COMMITTEE OF SOCIAL RIGHTS COMITÉ EUROPÉEN DES DROITS SOCIAUX



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Autism Europe v. Czech Republic Complaint No. 245/2025

COMPLAINT

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COLLECTIVE COMPLAINT

Autism-Europe v. the Czech Republic

For failure to ensure community-based social care services for all people with disabilities, including adults and children with autism, and ensure the rights of family caregivers

Violation of Articles 11§1, 11§ 3, 14§1, 14§2 and 16 and the equality principle of the European Social Charter

COMPLAINANT:

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SUMMARY

Autism-Europe, with the support of the Forum for Human Rights, has filed this collective complaint against the Czech Republic for its systemic failure to provide community-based social care services for individuals with disabilities, particularly those with autism, intellectual disabilities, and complex support needs. The complaint argues that the Czech Republic has violated several provisions of the 1961 European Social Charter by prioritising institutionalisation over independent living, failing to ensure adequate social care services for people with autism, intellectual disabilities, and challenging behaviour, and neglecting to provide sufficient support to informal caregivers, particularly by guaranteeing available and accessible respite services.

While the Czech Republic claims to support the right of people with disabilities to live in the community, its policies and funding choices tell a different story. Residential institutions continue to receive most public funding, leaving community-based services underdeveloped and inaccessible. As a result, especially individuals with autism, intellectual disability and challenging behaviour face prolonged and unnecessary psychiatric hospitalisations due to the lack of appropriate care alternatives. Their families, in turn, are left to shoulder the burden, experiencing exhaustion, financial hardship, and social isolation.

This complaint highlights the urgent need to take action to eliminate reliance on outdated and harmful institutional models, ensuring accessible, individualised, community-based social care services for all individuals with disabilities, including adults and children with autism, intellectual disabilities, and challenging behaviours. It underscores the devastating consequences of the Czech Republic's inaction—not only for individuals with disabilities but also for their families. Autism-Europe and Forum for Human Rights ask the European Committee of Social Rights to hold the Czech government accountable for violations of Articles 14§1 and 14§2, Articles 11§1 and 11§3, and Article 16 of the 1961 Charter, including the principle of equality embedded in the Preamble.

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I. PARTIES TO THE COMPLAINT

1.1. The complainant organisations

- 1. The International Association Autism-Europe (*hereinafter* "Autism-Europe") is an association governed by Belgian law of 25 October 1919 (as amended by the law of 6 December 1954) with headquarters in Brussels, whose primary purpose is to improve the lives of people with disabilities and caregivers, especially concerning people with autism. To achieve that aim, the association has a duty, in particular, to promote the dignity and rights of people with disabilities, and especially people with autism, in the spirit of international conventions and declarations; exercise vigilance so as to prevent all neglect of or negligence towards the people with disabilities and especially people with autism; and appropriately promote the care, education, guidance, training and well-being of children, young persons and adults with disabilities and especially autism.
- 2. Autism-Europe is supported in this collective complaint by the Central European non-governmental organisation, Forum for Human Rights (*hereinafter* "FORUM"). FORUM ensures that human rights are respected, protected, and fulfilled following relevant international human rights standards, employing litigation and advocacy to promote human rights before national and international human rights bodies. FORUM supports domestic and international NGOs and conducts and supervises litigation and advocacy activities at both domestic and international levels. FORUM has collaborated with various non-governmental organisations and aided in the preparation of several collective complaints, including those concerning the rights of persons with disabilities (see, for example, *Validity v Czech Republic*, collective complaint no. 188/2019).
- 3. Autism-Europe is an international non-governmental organisation with consultative status with the Council of Europe. In addition, it is included on the list established by the Governmental Committee of international non-governmental organisations entitled to lodge complaints. Further, Autism-Europe has particular competence regarding the complaint (see *Autism-Europe v. France*, no. 13/2002, decision on the admissibility of 12 December 2002).

1.2. The respondent State's European Social Charter obligations

4. This collective complaint has been lodged against the Czech Republic for failure to discharge its obligations under the Preamble (non-discrimination clause) and Articles 11§1, 11§3, 14§1, 14§2 and 16 of the 1961 European Social Charter (*hereinafter* "1961 Charter"). Autism-Europe, together with Forum, the national NGO, as the complainant organisations¹, claim that the Czech Republic failed in its duty to provide **people with disabilities, including adults and especially children with autism, intellectual**

¹ The complainants understand that national NGOs do not have standing before the Committee unless the Government has recognised that standing. This procedural provision disempowers national NGOs. Given that the procedural rules are not explicit, the complainants respectfully propose that the Committee expressly acknowledge the Forum for Human Rights' position, if not in the title of the collective complaint, then in the narrative part of its decisions.

disability and challenging behaviours, with available, affordable, and adequate social care services that would:

- a. Enable them to remain full members of society for as long as possible through the provision of services and facilities available for all people with disabilities and their opportunities to make use of them.
- b. Enable them to choose their lifestyle and to lead independent lives.
- c. Ensure their effective protection from discrimination and social isolation.
- d. Enable them to benefit from methods of social work.
- e. Provide them with the opportunity to take part in their establishment and maintenance.
- f. Ensure their effective protection as far as possible from the causes of ill health.
- 5. Moreover, the Czech Republic also failed in its duty towards informal caregivers.
- 6. The State Party ratified the 1961 Charter on 3 November 1999, accepting 52 of its 72 paragraphs, **including Articles 11, 14, and 16**. It signed the Revised Charter on 4 November 2000 but has not yet ratified it. Czechia ratified the 1995 Additional Protocol, which provided for a system of collective complaints, on 4 April 2012. Consequently, this complaint should be considered **admissible**.

II. OBLIGATIONS OF THE STATE PARTY

- 7. This collective complaint deals with the rights of people with disabilities who are dependent on the support of others, and especially people with autism, intellectual impairment and challenging behaviour. Further in the text, we will refer to this group for the sake of better readability as simply "people with disabilities", keeping in mind that this complaint concerns those groups that are significantly affected by the subject matter of this complaint: the failure to ensure their independent living.
- This collective complaint concerns the situation in the Czech Republic, which has been

 regrettably failing to provide persons with disabilities and their families, especially persons with autism, intellectual disability and challenging behaviour, a network of available, accessible, and adequate social care services.
- 9. As we will demonstrate, the reasons are fourfold:
 - *First*, in the Czech Republic, the **backbone of the existing system of social care services remains institutional** despite the State's claimed adherence to the right to independent living.
 - Second, the State has disproportionately favoured institutional settings over community services.
 - Third, the State has failed to plan social care and reflect the needs of people with disabilities adequately. As a consequence, not only has the deinstitutionalisation been failing, but specific groups of people with disabilities have been left without adequate social services. In other words, the State Party, which formally relies on the right of persons with disabilities to live independently, has put disproportionally more effort into maintaining and developing institutions than community social care services. At the same time, the State has been unable to

ensure the appropriate availability and accessibility of social care services to specific groups of persons with disabilities.

- Thus, fourth, as a result, for many people with disabilities and their families, there is (i) no choice and no social care services, only psychiatric hospitals, or (ii) their choice is limited to either accepting being housed in the institutions or trying to cope mainly with the support of families. The absence of adequate social care solutions leads to inadequate care and support, social isolation of persons with disabilities and, in the latter case, also of family caregivers who, further, have been facing unavailability and inaccessibility of respite services. The overview of the whole system, including relevant statistical data, is described in more detail below in Part III.
- 10. This collective complaint is based on four presumptions: (1) people with disabilities benefit from the right to independent living; (2) the Charter system recognises the right to independent living; (3) the right to independent living introduces concrete legal obligations and emphasises the rights of people in specifically vulnerable situations; (4) legal obligations concern, *inter alia*, ensuring availability and accessibility of appropriate social care services, deinstitutionalising the system of social care services if it depends on institutions, an obligation to develop and maintain network of available, affordable, and adequate outreach and ambulatory services, and ensuring special protection of families of people with disabilities.
- 11. The concept of independent living has been expressly recognised in international human rights law under **Article 19 of the UN Convention on the Rights of Persons with Disabilities** (*hereinafter* "CRPD"). Although we consider Article 19 CRPD relevant to the present collective complaint, we focus on the rights of persons with disabilities enshrined directly in the 1961 Charter. Relevant provisions are:
 - a. Article 11§1 of the 1961 Charter guarantees everybody the right to protection of health and the corresponding obligation of the State to "undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia to remove as far as possible the causes of ill health"; and Article 11§3 of the 1961 Charter guarantees prevention of epidemic, endemic and other diseases.
 - b. Article 14§1 of the 1961 Charter enshrines the right of everybody to benefit from social welfare services and the corresponding obligation of the State to "undertake to promote or provide services which, by using methods of social work, would contribute to the welfare and development of both individuals and groups in the community, and to their adjustment to the social environment".
 - c. Article 14§2 of the 1961 Charter provides for the right of users of social services to participate, either directly or through voluntary or other organisations in establishing and maintaining those services.
 - d. Article 16 of the 1961 Charter guarantees families the right to social, legal and economic protection by requiring the State to ensure "the necessary conditions for the full development of the family, which is a fundamental unit of society", through social and family benefits, fiscal arrangements, provision of family housing, benefits for the newly married, and other appropriate means.

- 12. The right not to be discriminated against is also relevant in the context of the present collective complaint. The 1961 Charter does not contain any specific non-discriminatory provision as the Revised Charter (Article E) but includes a non-discrimination clause in its Preamble. The European Committee of Social Rights (hereinafter "the Committee") has already held in respect of the Preamble to the 1961 Charter that "one of the underlying purposes of the social rights protected by the Charter is to express solidarity and promote social inclusion. It follows that the States must respect difference and ensure that social arrangements are not such as would effectively lead to reinforcing social exclusion."²
- 13. From the formal point of view, the non-discrimination clause in the Preamble must be explicitly mentioned, especially for the alleged violations of Article 14§1, Article 14§2, Article 11§1 and/or Article 11§3 and Article 16 of the 1961 Charter.
- 14. Below, we focus, first, on the listed provisions of the 1961 Charter in more detail. Following this analysis, we further provide a brief overview of the relevant provisions of international human rights law, especially the CRPD.

2.1. Article 14§1 of the 1961 Charter

- 15. Article 14§1 of the 1961 Charter is relevant as the Committee's case law and conclusions on Article 14§1 of the 1961 Charter bring **important principles and guidance on interpreting the concept of independent living**.³ Furthermore, Article 14§1 of the 1961 Charter explicitly states that social services for persons in need of them must be **based on methods of social work** a requirement that institutional services are never eligible to comply with. It is worth noting that the wording of Article 14§1 is the same both in the 1961 Charter and the Revised Charter. We will thus also refer to the case law and conclusions relating to the Revised Charter.
- 16. The Committee emphasised that to comply with the requirements of Article 14§1 of the 1961 Charter the social welfare services must meet two qualitative requirements:

 they must use methods of social work, and 2) they must contribute to the welfare and development of both individuals and groups in the community and to their adjustment to the social environment.⁴ The Committee explicitly explained that the specific methods of social work used by the social welfare services together with the general scope of coverage distinguished Article 14 from the other relevant provisions of the 1961 Charter.⁵ The requirements to be based on methods of social work and to adjust beneficiaries to social environment show that Article 14§1 of the 1961 Charter

² ECSR, *European Roma Rights Centre (ERRC) v. Italy*, complaint no. 27/2004, decision on the merits of 7 December 2004, § 19.

³ For instance, concerning Article 4 of the 1988 Additional Protocol and the affordability of supportive social services, see ECSR, *Central Associations of Carers in Finland v. Finland*, complaint no. 71/2011, decision on the merits of 4 December 2012, § 49.

⁴ Conclusions I – Statement of interpretation – Article 14, 1 January 1965 – 31 December 1967, I_Ob_-52/Ob/EN.

⁵ Conclusions 2009 – Statement of Interpretation – Article 14-1, 2009_163_02/Ob/EN.

pursue an inclusive objective⁶ and that services based on segregation and isolation are not compatible with that provision.

- 17. The Committee confirmed the broad scope of Article 14§1 of the 1961 Charter, both as to its *ratione personae* as well as *ratione materiae*. The Committee emphasised that the provision applied to a large number of beneficiaries, not only those who do not have adequate resources as foreseen by Article 13§3 and that it covered not only assistance but **"any action taken to facilitate the development of individuals and their adjustment to society"**.⁷ (emphasis added).
- 18. Further, the Committee stressed the dynamic nature of the provision because "the social welfare services for which it provides are designed to keep on increasing and broadening their action".⁸ In other words, there is a robust progressive objective that can be translated into the requirement for transforming the social services system wherever it is based on segregating forms of services, as well as wherever it fails to support people with disabilities and their families.
- 19. In International Federation of Human Rights (FIDH) v. Belgium (collective complaint no. $75/2011)^9$, the Committee had the opportunity to assess the situation of persons with disabilities that is very similar to the subject matter of the present collective complaint. The collective complaint challenged the insufficient number and variety of care solutions for highly dependent persons with disabilities, i.e. "persons who need the help of others to perform the ordinary daily activities essential to survival and/or the realisation of their goals in life."¹⁰ In its decision, the Committee clarified what equal and effective access to social welfare services in terms of Article 14§1 of the 1961 **Charter** means. The Committee, especially, connected the requirement of equal and practical accessibility of social welfare services to the existence of a free choice of their beneficiaries. In concrete, the Committee held that "under Article 14§1 of the Charter, access of persons with disabilities to social welfare services can be regarded as equal and effective if the State Party offers varied and multiple methods of care for these people by the community and if the number and quality of the social welfare services actually provided correspond as closely as possible to the specific, practical, individual needs of the persons concerned so that a free choice can be made by the users concerned and, above all, by their families, provided that they act on behalf of these persons and not instead of them."11 (emphasis added).
- 20. It is worth noting that the requirement that the beneficiaries of social welfare services are provided with free choice, which exists not only in law but also in practice, also constitutes the core of the right to independent living as enshrined in Article 19 of the CRPD. As it appears, there is a **strong relation between Article 14§1 of the Charter**

⁶ Inclusion is also one of the fundamental principles of social work. See for instance the Global Social Work Statement of Ethical Principles adopted by the International Federation of Social Workers which links inclusion with the idea of social justice (Principle 3 – Promoting social justice). Inclusion is explicitly mentioned in Principle 3.2 Respect for diversity and 3.5 Building solidarity. The Statement is available at: <u>https://www.ifsw.org/globalsocial-work-statement-of-ethical-principles/</u> [accessed 15 November 2023].

⁷ Conclusions I – Statement of interpretation – Article 14, 1 January 1965 – 31 December 1967, I_Ob_-52/Ob/EN. ⁸ *Ibid*.

⁹ ECSR, International Federation of Human Rights (FIDH) v. Belgium, complaint no. 75/2011, decision on the merits of 18 March 2013.

¹⁰ Ibid, § 64.

¹¹ Ibid, § 110.

and Article 19 CRPD. The Committee confirmed that relation by directly referring to Article 19 CRPD in its decision.¹² The Committee further emphasised that free choice of social welfare services beneficiaries was linked with the existence of alternatives.¹³ The Committee recognised that States dispose of a margin of appreciation in choosing a method of community care for persons with serious disabilities and deciding which is the most appropriate and most closely matches their needs.¹⁴ Nevertheless, it recalled that Article 14§1 of the Charter "may be undermined if the approach which may reasonably be regarded, within the margin of appreciation of the State, as being most suited to the needs of these persons is particularly deficient".¹⁵ In other words, the Committee rejected the idea of a too wide space of discretion for the relevant authorities, depriving the right enshrined in Article 14§1 of the 1961 Charter of its practical effectiveness for persons in need of social welfare services. The Committee emphasised that the space of discretion cannot be so wide to enable the State to resort to forms of collective care that have nothing to do with social work.¹⁶

- 21. In the decision, the Committee also confirmed that the right enshrined in Article 14§1 of the 1961 Charter is one of **progressive realisation**. Nevertheless, the State is in breach of this provision if it fails to comply with the legal obligation to offer a particular social service to the extent that **it denies access to this service to the persons concerned and excludes them from any solution of this type**.¹⁷ That Committee's finding corresponds to the concept of **minimum core obligations** appearing in the documents of UN treaty bodies.¹⁸
- 22. The Committee further summarised its case law relating to the progressive realisation of rights enshrined in the 1961 Charter. It emphasised that whenever the implementation of the right is exceptionally complex and expensive, **the State still must not resign itself to fulfilling it**. The criteria to assess the State's actions in the field are (i) a reasonable timeframe, (ii) measurable progress, and (iii) financing consistent with the maximum use of available resources.¹⁹ Those criteria must also be relevant for deinstitutionalising a system based predominantly on institutional services, such as the system of social care in the Czech Republic, as well as designing a system that would be inclusive of all persons with disabilities, including those who demonstrate challenging behaviour. Again, the States have the margin of appreciation in determining the steps to be taken. They must balance the general interest and the interest of a specific group and make choices regarding priorities and resources. Nonetheless, they still must be particularly mindful of the impact of their choices on groups with heightened vulnerabilities. They must take "practical action to give full

¹² Ibid, §§ 112 and 113.

¹³ Ibid, § 114.

¹⁴ Ibid, § 121.

¹⁵ Ibid, § 122.

¹⁶ Ibid, § 136.

¹⁷ Ibid, § 145.

¹⁸ The UN Committee on Economic, Social and Cultural Rights defined minimum core obligations in its General Comment No. 3 of 1990. In line with this definition, minimum core obligations are those obligations that serve "to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights". See the General Comment of the UN Committee on Economic, Social and Cultural Rights No. 3, 1990, para. 10.

¹⁹ ESCR, *International Federation of Human Rights (FIDH) v. Belgium*, complaint no. 75/2011, decision on the merits of 18 March 2013, § 145.

effect to the rights recognised in the Charter".²⁰ In other words, **the States must reflect those who are in a situation of particular vulnerability, such as people with autism, intellectual disability and challenging behaviour, and their families.**

- 23. Further, we would like to mention a more recent Committee's decision on the merits in the case of the *European Disability Forum (EDF) and Inclusion Europe v. France*, no. 168/2018.²¹ That decision is particularly relevant regarding **the relationship between Article 14§1 of the Charter and Article 15§3 of the Revised Charter**. As mentioned in the introduction, the Czech Republic has still not ratified the Revised Charter and, unfortunately, the 1961 Charter does not contain an appropriate corresponding provision to Article 15 of the Revised Charter, guaranteeing the right of persons with disabilities to independence, social integration, and participation in the life of the community. The respective provision of the 1961 Charter does not cover the complex issue of social inclusion of persons with disabilities but rather focuses on the integration of persons with disabilities in the employment and labour market.
- 24. Nevertheless, as the cited Committee's decision shows, that does not necessarily mean that the rights and principles enshrined in Article 15 of the Revised Charter, at least regarding access to social support services, do not equally apply to State Parties bound by the 1961 Charter. It should be noted that the complainant organisations in the cited case also alleged a violation of Article 14§1 of the Revised Charter, but the Committee decided not to examine that allegation separately, arguing that "in the circumstances of this case, the allegations made with regard to those rights can be regarded as subsumed within the wider question of whether Article 15§3 of the Charter has been satisfactorily applied."²² This confirms that there is a closed relation between the two provisions, with Article 14 of the 1961 Charter being a general provision as far as social welfare services for persons with disabilities are concerned. Of course, Article 15 of the Revised Charter as a special provision may guarantee a higher standard compared to Article 14 and the principles and rules relating to Article 15 of the Revised Charter thus may not be entirely transferable to Article 14. That is for the Committee to decide. We argue, however, that the idea that the Charter is a living instrument and must be interpreted in present-day conditions requires that the relevant international human rights standards²³, including the CRPD²⁴, define a perspective on how Article 14 of the Charter should be interpreted. This makes the Committee's findings under Article 15 of the Revised Charter concerning access to social welfare services relevant in interpreting Article 14 of the 1961 Charter.
- 25. The abovementioned decision addressed several issues falling within Article 15§3 of the Revised Charter. We want to concentrate on those relating to social welfare services for persons with disabilities and caregivers and thus relevant in our view in terms of Article 14§1 of the 1961 Charter as well. What we find as the common point

²⁰ Ibid, § 145.

²¹ ECSR, *European Disability Forum (EDF) and Inclusion Europe v. France*, complaint no. 168/2018, decision on the merits of 19 October 2022.

²² Ibid, § 106.

²³ Digest, 2022, p. 34.; See also, for instance, ECSR, *European Roma Rights Centre (ERRC) and Mental Disability Advocacy Centre (MDAC) v. Czech Republic*, complaint No. 157/2017, decision on the merits of 17 June 2020, §§ 132 and 133.

²⁴ ESCR, *International Federation of Human Rights (FIDH) v. Belgium*, complaint No. 75/2011, decision on the merits of 18 March 2013, §§ 111 and 112.

of the case dealt with in the cited decision and the subject matter of the present collective complaint is a situation of massive institutionalisation of persons in a situation of dependency, which is a result of the State's failure to properly manage social care services and ensure available, appropriate, and affordable social services. The complainant organisations in the cited case argued that France failed to provide sufficient resources to assist persons with multiple disabilities and to develop support services in mainstream settings.²⁵

- 26. Further, in this decision, the Committee rejected the idea that institutionalisation would be an appropriate form of support in compliance with the requirements of Article 15§3 of the Revised Charter.²⁶ The Committee emphasised the importance of the person's free choice concerning social services and the person's life, including where and with whom the person lives.²⁷ It is worth noting that this understanding of the right enshrined in Article 15§3 of the Revised Charter is very close to the content of the right to independent living guaranteed in Article 19 CRPD and interpreted in the UN CRPD Committee's General Comment no. 5. The close relation of Articles 14 of the Charter and 15§3 of the Revised Charter thus supports the already drawn connection between Article 14§1 of the 1961 Charter to CRPD, its paradigmatic background, and its provisions, at least concerning persons with disabilities. In line with the rights-based model of disability and the concept of inclusive equality promoted by the CRPD, the Committee held that there was a "strong presumption that any practice (whether intentional or otherwise) that involves or results in the isolation of persons with disabilities is not in conformity with this right. For the Committee, therefore, under Article 15§3, the States Parties must make support services available to ensure full integration and participation by persons with disabilities in the life of the community."28
- 27. The Committee held that Article 15§3 of the Revised Charter requires support services, such as personal assistance and auxiliary aids, to be available, either for free or subject to an appropriate contribution considering the beneficiary's means.²⁹ Thus, as in the case of Article 14§1 of the Charter, it stressed not only the availability of appropriate support services but also their **affordability for their beneficiaries**. We argue that the Committee's approach to affordability has a strong individual dimension. It requires ensuring that the existing social support services are affordable to everyone who may need them so that they are practical and effective. Furthermore, directly in the cited decision, the Committee underlined the importance of financial support in making accessible a range of individualised support services (home assistance, self-care etc.)³⁰ and emphasised that "the process for selecting and organising the services to be covered by the financial support excludes any "one size fits all" approach and

²⁵ ECSR, *European Disability Forum (EDF) and Inclusion Europe v. France*, complaint No. 168/2018, decision on the merits of 19 October 2022, §§ 126 and 127.

²⁶ Ibid, § 186.

²⁷ Ibid

²⁸ Ibid

²⁹ Ibid, § 181.

³⁰ Ibid, § 201.

allows the identification of the person's preferences in professional or recreational life and medical needs, etc."³¹

- 28. Indeed, the Committee relied on its case law relating to situations when achieving one of the rights enshrined in the Charter is exceptionally complex and particularly expensive.³² Although France has already adopted several steps to address the deficiencies of the national system of support services for persons with disabilities, **it did so with considerable delays**. The Committee thus concluded that France failed "to adopt effective measures to remedy the long-standing problems related to inadequate access to social support services within a reasonable timeframe".³³ As we will demonstrate below, the situation in the Czech Republic is even worse since the Czech Republic has failed to address the needs of certain groups of persons with disabilities who face unavailability of any social care services, let alone community-based services, resulting in unnecessary and/or unwanted prolonged psychiatric hospitalisations.
- 29. To conclude, considering the subject matter of the present collective complaint, Article 14§1 of the 1961 Charter is a crucial provision. First, it underlines the right of free choice and its dependence on the existence of alternatives in practice. Second, it provides the background to draw a solid link to Article 19 CRPD and the guaranteed right to independent living. *Third*, it opens the space to make the rights enshrined in Article 15§3 of the Revised Charter relevant also in the context of the 1961 Charter, at least in its part relating to the existence of social welfare services. To summarise, Article 14 of the 1961 Charter enables formulating strong grounds for the argument that the architecture of the system of social welfare services must provide the beneficiaries with enough options, including outreach and ambulatory services, to allow them to make a free choice of what type of support they wish to use. To this end, the alternative options must be available, accessible, and affordable for the beneficiaries, especially for those who are in a particularly vulnerable situation. Furthermore, from Article 14 of the 1961 Charter it follows that wherever the system relies predominantly on institutions, the State must proceed to its deinstitutionalisation.
- 30. Yet would the Committee believe that the provision of Article 11§3 of the 1961 Charter is more appropriate concerning specific arguments presented in this collective complaint, specifically regarding deinstitutionalisation (see Conclusions XXII-2 (2021) on the Czech Republic, p. 20) and the situation of children with autism, intellectual disabilities and challenging behaviour who are forced to inappropriate and prolonged psychiatric hospitalisations (see paras. 107-117 below), the complainants consider that the situation in the State Party is not in conformity also with this provision. In the opinion of the complainants, Article 14 of the 1961 Charter is a logical perspective for this collective complaint. It can be read as subsuming Article 11§3 of the 1961 Charter concerning the problem of deinstitutionalisation and inappropriate psychiatric hospitalisations, however, if the Committee is of another opinion, it is argued that the relevant principles and perspectives, as discussed above, should be *mutatis mutandis*, applied also within the framework of Article 11§3 of the 1961 Charter.

³¹ *Ibid*, § 202.

³² *Ibid*, §§ 180 and 191.

³³ Ibid, § 199.

2.2. Article 14§2 of the 1961 Charter

- 31. Article 14§2 of the 1961 Charter requires State Parties to encourage **the participation** of individuals and voluntary or other organisations in establishing and maintaining social welfare services. This right is not only about the freedom of voluntary associations to establish private social welfare services but also about **the right of those for whom social welfare services are designed to participate in maintaining them**. For the present collective complaint, we find the latter aspect particularly important. The Committee interprets Article 14§2 of the Charter as inviting "to strengthen the dialogue with civil society in areas of welfare policy which affect the social welfare services". This requires "promote representation of specific user–groups in bodies where the public authorities are also represented, as well as action to promote consultation of users on questions concerning the organisation of the various social services and the aid they provide."³⁴
- 32. Based on the Committee's findings, we argue that Article 14§2 of the 1961 Charter can be read, *inter alia*, as an expression of **the principle "nothing about us without us"** applied in the specific area of social services support. The principle is **a cornerstone of the disability rights movement**³⁵ and, as such, constitutes one of the fundamental principles of the CRPD (Article 3§3; participation is also one of the dimensions of inclusive equality), part of general obligations (Article 4§3), and also rights enshrined therein (Articles 29 Participation in political and public life, 30 Participation in cultural life, recreation, leisure and sport, and 33§3 Participation in the monitoring process).
- 33. In addition, participation is an inherent part of the right to independent living enshrined in Article 19 CRPD, where it also takes very **concrete individual dimensions**, either in the form of the requirement of **self-management of personal assistance**³⁶ and in the form of **the requirement of acceptability of disability support services**.³⁷
- 34. Thus, Article 14§2 of the Charter and the CRPD, including Article 19, can suitably complement each other because the CRPD and general comments relating thereto provide an overview of **the multi-layered nature of the right to participation. At the same time,** Article 14§2 of the 1961 Charter provides **a ground to make the right to participation more universal** and apply it not only to persons with disabilities but **also to other persons using social welfare services.** The UN CRPD Committee requires the participation of persons with disabilities to be meaningful.³⁸ This requirement aligns with the Committee's call for the rights enshrined in the Charter to be not only formal but also practical and effective. We find this requirement crucial for the present collective complaint since the system to ensure the participation of people with disabilities and caregivers in the process of drafting and adopting the State's policy in social welfare services and in planning their practical establishment and maintenance is **unsatisfactory in the Czech Republic** and practically makes those persons rather objects than subjects of those policies and processes (see below paras. 102-106).

³⁴ Digest, June 2022, p. 134.

³⁵ CRPD/C/GC/7, para. 4.

³⁶ CRPD/C/GC/5, para. 16 (d) (iv).

³⁷ *Ibid*, para. 60.

³⁸ CRPD/C/GC/7, paras. 1, 4, 8, 22, 47 and 78.

2.3. Article 11 of the 1961 Charter

- 35. Moreover, the complaining organisations consider it essential to thematise the subject matter of the present collective complaint from the perspective of the right to the highest attainable standard of health as enshrined in Article 11 of the 1961 Charter. Article 11§1 of the Charter requires State Parties to promote that right by taking appropriate measures to remove the causes of ill health as far as possible. We argue that the situation when a person cannot freely choose the form of support and has no other choice than leaving for an institution, including unnecessary hospitalisation in a psychiatric hospital, should be considered as a cause of ill health and be addressed as such.
- 36. This position can be supported by reports of the UN Special Rapporteurs on the right to health. In 2005, the then UN Special Rapporteur on the right to health, Paul Hunt, described the segregation and isolation of persons with mental disabilities in institutions due to the lack of community-based services as a violation of the right to health.³⁹
- 37. Then, in 2018, Danius Pūras, pointed out that the right to health is violated whenever a person is subjected to confinement without their informed consent.⁴⁰ By confinement, he meant "a term widely used in health and social welfare settings to indicate the restriction of an individual within a limited area, following medical or social-welfare advice."⁴¹ We argue that when outreach and ambulatory alternatives to institutions are not practically available and affordable, consent with institutionalisation in a residential setting cannot be considered free. Moreover, we argue that this type of confinement is demonstrated by appalling circumstances when people with disabilities, typically with autism, intellectual disability and challenging behaviour, including children, end up hospitalised in psychiatric hospitals, even though they need social services support. There is, thus, a violation of the right to health on the grounds of a failure to ensure that people with disabilities can freely choose the form of their support.
- 38. In the cited report, Dainius <u>Pūras</u> also described the adverse impact on deprivation of liberty or confinement: "the most silent forms of adverse conditions of detention and confinement, including boredom and powerlessness, can often prove to be the most severe, notably affecting mental health while giving rise to feelings of hopelessness and despair and suicide attempts."⁴² He thus concluded that "overall, centres of detention or confinement are not therapeutic environments" and emphasised that the underlying determinants of health also included "the creation and maintenance of non-violent, respectful and health relationships in families, communities and society at large". Unfortunately, such relationships cannot be established in detention or confinement, which hinders the full and practical realisation of the right to health. The UN Special Rapporteur on the right to health noted that "even with noble efforts to

³⁹ E/CN.4/2005/51, paras. 85–86.

⁴⁰ A/HRC/38/36, para. 6.

⁴¹ *Ibid*, para. 5.

⁴² *Ibid*, para. 32.

establish a strong culture of respect and care, violence and humiliation usually prevails, adversely affecting the development of healthy relationships."⁴³

- 39. Further, in his report *Mental Health and Human Rights: Setting a Rights-based Global Agenda*, Danius Pūras, acting as the UN Special Rapporteur on the right to health, **included among the underlying determinants of health social inclusion,** which he also identified as one of the key principles of the rights-based approach to mental health. He emphasised that "securing interpersonal, community and broader connections with society is an essential psychosocial determinant of mental health and vital to the promotion and protection of the right to mental health, including at the intervention level. Social exclusion is a universal experience for persons with intellectual, cognitive or psychosocial disabilities, which symbolizes a core obstacle to recovery and the full enjoyment of their right to mental health." The UN Special Rapporteur **listed the culture of institutional and segregated care among the reasons for social exclusion**.⁴⁴
- 40. We argue that the cited findings and conclusions enable us to connect unnecessary and/or unwanted institutionalisation with detrimental effects on the person's health, including when it concerns unnecessary and/or unwanted hospitalisations of people with autism, intellectual disability, and challenging behaviour in psychiatric hospitals. As such, institutionalisation becomes a practice that raises concerns under Article 11, especially Article 11§1 of the 1961 Charter because it can be considered as a cause of ill health and shall be eliminated as far as possible.

2.4 Article 16 of the 1961 Charter

- 41. The complainants further argue that the situation in the Czech Republic is not in conformity with Article 16 of the 1961 Charter because of the lack of care solutions and social services tailored to the needs of individuals with disabilities, forcing many families, and especially families of people with autism and intellectual disability, into precarious situations. In EDF and Inclusion Europe v. France (complaint No. 168/2018, the decision on the merits of 19. 10. 2022, § 304) and FIDH v. Belgium (complaint no. 75/2011, the decision on the merits of 18 March 2013, §183), the Committee made clear that under Article 16 of the Charter, the provision of appropriate care for highly dependent persons with disabilities by the community is in no way incompatible with their families' involvement in the lives of the persons concerned, or even with duty for their families to sustain a constant, good quality relationship with them. The Committee nonetheless took the view that the relationship is fundamentally altered when families assume care and living support tasks for their relatives with severe disabilities, which could have been properly performed, in close cooperation with the family, by social services appropriate to these persons' needs. The Committee reflected that these considerations are valid not only in the case of persons with severe disabilities but of all persons with disabilities who need support and care.
- 42. In assessing the situation of caregivers, the Committee relied on testimonies provided in letters from caregivers (*FIDH v. Belgium*, § 184) or on the testimonies and examples collected by domestic NGOs, showing that the service shortage obliges persons with

⁴³ *Ibid*, para. 33.

⁴⁴ A/HRC/44/48, para. 59.

disabilities to live with their families, with far-reaching negative implications for the family's living conditions in many cases (*EDF and Inclusion Europe v. France*, § 305). Further, in both cases, the Committee noted that "for many family members of persons with disabilities, the consequence of their devotion to another family member with disabilities is that they have to reduce their working hours or give up work altogether to take care of their highly dependent family member" (*FIDH v. Belgium*, § 184; *EDF and Inclusion Europe v. France*, § 306).

43. Apart from the impact of care on the professional activities of informal caregivers (EDF and Inclusion Europe v. France, § 309), the Committee considered, in general, that the shortage of care solutions and of social services adapted to the needs of persons with severe disabilities causes many families to live in precarious circumstances, undermining their cohesion (FIDH v. Belgium, § 187). In this regard, indeed, according to the well-established position of the Committee, the States Parties must be particularly mindful of the impact that their choices will have for groups with heightened vulnerabilities, such as persons with disabilities, as well as for the other persons affected including, especially, their families on whom falls the heaviest burden in the event of institutional shortcomings (Autism-Europe v. France, complaint No. 13/2002, § 53).

2.5 Non-discrimination clause under the 1961 Charter

- 44. The 1961 Charter does not contain an explicit provision instituting the prohibition of discrimination. The non-discrimination clause is, however, part of its Preamble. The Committee has repeatedly recalled that "issues of discrimination may be examined in light of the Preamble of the 1961 Charter in conjunction with substantive rights of the 1961 Charter".⁴⁵
- 45. Human rights law already provides a strong background to support this position. In its General Comment no. 5, the UN Committee on Economic, Social and Cultural Rights marked segregation and isolation achieved through the imposition of physical and social barriers as subtle forms of discrimination.⁴⁶ The unavailability or unaffordability of alternatives to segregating and isolating services may be considered a social barrier.
- 46. Further, the UN CRPD Committee thematised the right to independent living and inclusion in society as a dimension of the more general right not to be discriminated against on the grounds of a disability.⁴⁷ This makes the availability and affordability of services needed for independent living directly an aspect of the right not to be discriminated against on the grounds of a disability.
- 47. We also consider it helpful to refer to the concept of inclusive equality to understand the discriminatory dimension of the subject matter of the present collective complaint. The UN CRPD Committee formulated the concept to address the multidimensional nature of substantive equality. The concept of inclusive equality should express that the situation of substantive equality of persons with disabilities consists of four

⁴⁵ ECSR, *International Commission of Jurists (ICJ) v. Czech Republic*, complaint No. 148/2017, decision on the merits of 20/10/2020, § 49.

⁴⁶ General Comment of the UN Committee on Economic, Social and Cultural Rights No. 5, 1994, para. 15.

⁴⁷ CRPD/C/GC/5, para. 18.

dimensions: (a) a fair redistributive to address socioeconomic disadvantages; (b) a recognition dimension to combat stigma, stereotyping, prejudice and violence and to recognise the dignity of human beings and their intersectionality; (c) a participative dimension to reaffirm the social nature of people as members of social groups and the full recognition of humanity through inclusion in society; and (d) an accommodating dimension to make space for difference as a matter of human dignity.⁴⁸

- 48. The concept of inclusive equality, as defined by the UN CRPD Committee, enables us to thematise the lack of free choice of the form of support, which leads to spatial and social segregation of persons in a situation of dependency as a form of systemic/structural discrimination. A system that relies dominantly on institutional solutions for people with disabilities and for some groups of people with disabilities especially, such as children with high-level needs, does not make outreach and ambulatory alternatives available and affordable for the beneficiaries and fails to meet all four dimensions of inclusive equality.
- 49. First, redistributing public funds in a way that does not support the availability and affordability of outreach and ambulatory alternatives to institutions does not mitigate the socioeconomic disadvantage of persons needing support services. On the contrary, it further widens the property gap, making people face poverty or disadvantageous socioeconomic conditions. At the same time, the outreach and ambulatory forms of support are available and affordable only for those with sufficient financial resources. Second, the system that does not ensure the real choice of the form of support and favours the institutional solution inevitably fails to recognise those in need of support as active and valuable members of the community. Instead, it treats them as passive objects of care. It thus fails to meet the recognition dimension of inclusive equality. Third, it also fails to meet the participative dimension because it does not consider the views of those who prefer to choose outreach and ambulatory services as relevant. Fourth, such a system does not accommodate diversity because it does not create enough space to individualise the form of support to match as much as possible the views and needs of the person to whom it is delivered. Considering this, we will argue that the situation in the Czech Republic is not in conformity with the above-mentioned provisions of the 1961 Charter read in the light of the principle of equality.

III. THE SITUATION IN THE CZECH REPUBLIC

- 50. This section is divided into eight subsections. We start by explaining the legal and policy framework (3.1). Then, we show and interpret the statistics proving that the social services system depends on residential settings (3.2). We then explain that the data proves the unavailability and inaccessibility of community-based social care services, both residential (3.3) and non-residential (3.4).
- 51. In the following subsections, we describe in detail the leading causes for the failure to comply with the right to independent living, as identified mainly by the Czech

⁴⁸ CRPD/C/GC/6, para. 11.

Ombudsperson⁴⁹ and independent research⁵⁰. Specifically, we discuss the failure to properly plan the network of social care services (3.5.) and adequately finance social care services (3.6.). After that, we show how these failures affect groups of people in specifically vulnerable situations, namely people with high-level needs, such as people with autism, intellectual disability and challenging behaviour (3.7.) and their informal caregivers (3.8.).

52. Considering the presented data and information from reliable sources, we argue that the situation described in the Czech Republic is not in conformity with the 1961 Charter, especially with Articles 14§1, 14§2, 11§1, 11§3, and 16 of the 1961 Charter and the prohibition of discrimination embedded in the Preamble to the 1961 Charter.

3.1. General legal and policy framework

- 53. The Social Services Act no. 108/2006 regulates the social services system in the Czech Republic. In 2010, the Czech Republic ratified the UN CRPD. In 2012, the Social Services Act was amended to implement Article 19 of the CRPD. Namely, Article 38 of the Social Services Act, since 2012, provides that all persons with disabilities have the right to be provided with social services "in the least restrictive environment".⁵¹
- 54. Since 2010 and 2012, there has been a clear legal obligation to ensure that all people with disabilities, regardless of their needs, are provided with community-based social services. The law does not contain an express obligation to deinstitutionalise existing institutional settings.
- 55. The law does not define the community-based social care service. However, in December 2024, the lower chamber of the Czech Parliament adopted an amendment to the Social Services Act and introduced a definition of a community-based service. Under new Article 33a, community-based services should be defined as follows:

⁴⁹ Czech Ombudsperson Research Report. Deinstitucionalizace a transformace sociálních služeb – přístup krajů a Ministerstva práce a sociálních věcí ve strategických dokumentech [Deinstitutionalisation and transformation of social services - the approach of regions and the Ministry of Labour and Social Affairs in strategic documents]. Brno, 2023. The report is available in Czech at:

https://www.ochrance.cz/projekty/posileni-aktivit/deinstitucionalizace a transformace socialnich sluzeb.pdf ⁵⁰ We rely mainly on two recent research reports:

^{1.} Klusáček, J., Adamcová, M. Žít jako ostatní [Live like the others]. Prague: JDI & SPMP, 2021. The report is available in Czech at: <u>https://jdicz.eu/zit-jako-ostatni-jdi-a-spmp-2021/</u>

^{2.} Paleček, J., Kocman, D., Valinová, L. *Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR* [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Prague: Abakus, 2024. The report is available in Czech at:

https://abakus.cz/file/ke-stazeni/Stale na zacatku Zprava o stavu socialni politiky a sluzeb v CR.pdf

⁵¹ According to the explanatory report: "The proposed amendment responds to the ratification of the UN Convention on the Rights of Persons with Disabilities by the Czech Republic in 2009 and fully complies with the obligations under Articles 3 and 19 of the Convention. The amendment is also in line with other UN documents. The proposed text regulates the right of all users of social care services to receive care in the least restrictive environment. It complements existing legislation and thus creates a complete framework for the provision of social care services that emphasises autonomy, non-discrimination and inclusion of people with disabilities."

"(1) Outreach services, ambulatory services and residential services referred to in Article 47 to 51⁵² which are provided in such a way as to enable a person to live independently in a way that corresponds by its nature to the normal life of persons of his or her age and to prevent his or her segregation shall be referred to as community services.

(2) The location of an outpatient service provided as a community service shall not result in the creation of localities with a higher number of persons for whom the social service is intended. Residential services provided as community-based services shall be provided only in an apartment, condominium, or single-family dwelling located within the general development of the municipality. The location of a residential service provided as a community service shall not lead to the creation of localities with a higher number of persons for whom the social service is intended and to the creation of an environment different from the normal municipal community.

(3) The implementing regulations shall set out the requirements for the location of outpatient and residential services provided as a community service in a locality and the maximum capacity criteria for the location of a residential service provided as a community service in a locality and in a residential building."

- 56. Under the Social Services Act, **regions** are responsible for ensuring the availability and accessibility of social services, including community-based services. Each region is an administrative self-governing unit. The Czech Republic is divided into 14 regions, each with specific and crucial competence regarding social services.
 - Under Article 95(g) of the Social Services Act, the region must ensure the availability of social services within its territory. The idea is that it must meet the needs of people living within the region's territory;
 - In this regard, the region must, following Article 95(d) of the Social Services Act, adopt a mid-term plan for the development of social services (hereinafter "the regional plan"). There are 14 regional plans, which are crucial policy documents for social services development;
 - Moreover, under Article 95(h) of the Social Services Act, the region defines the socalled network of social services. The region sets the overall regional service capacity (in Czech *"síť služeb"*), which specifies the capacity volume of service providers eligible for public funding;
 - Apart from their commissioning role, the regions have a second, conflicting role; they are also the most significant providers of residential social care in the Czech Republic.
- 57. Under Article 96 of the Social Services Act, the Ministry of Social Affairs must adopt the national strategy for developing social services in the Czech Republic (hereinafter "the national plan"). Thus, there is national plan and 14 regional plans. Moreover, under Article 96, the Ministry of Social Affairs must "define parameters of availability of social care services."

⁵² These Articles refer to specific types of social services. These types are, namely: Weekly stationary service providers (Art. 47), homes for people with disabilities (Art. 48), homes for elderly people (Art. 49), homes with special regimes (Art. 50), and sheltered housing (Art. 51).

- 58. The Act Social Services Act distinguishes (i) outreach services, (ii) ambulatory services, and (iii) residential services.
- 59. In terms of policy documents, currently, there are:
 - 2016-2025 National Strategy of the Development of Social Care Services⁵³
 - 2023-2025 Action Plan for transitioning of social services to community-based care and greater individualisation of care and to promote deinstitutionalisation of social services in the Czech Republic⁵⁴
 - National Plan for the Promotion of Equal Opportunities for Persons with Disabilities 2021-2025⁵⁵
 - Systemic measures to support people with intellectual and challenging behaviour for the period 2024-2030⁵⁶

3.2. The social care system is dependent on non-community-based residential care

- 60. As mentioned above, the Czech Republic's social care services system, regulated by the Social Services Act, distinguishes: (i) outreach services, (ii) day services, and (iii) residential services.
- 61. Under Article 33, *residential services* are connected with accommodation in social service facilities (Article 33§2). *Day services* mean services for which a person attends is accompanied by or is transported to a social services facility. The service does not include accommodation (Article 33§3). *Outreach services* are provided to a person in their natural social environment (Article 33§4).
- 62. There are various residential social care services where people with disabilities are accommodated, especially⁵⁷:
 - weekday residential care services (Article 47, in Czech, "týdenní stacionář"),
 - residential homes for people with disabilities (Article 48, in Czech, "domov pro osoby se zdravotním postižením"),
 - special regime residential homes (Article 50, in Czech, "domov se zvláštním režimem"),
 - sheltered housing (Article 51, in Czech, "chráněné bydlení").

 ⁵³ The document is available online in Czech at: <u>https://www.mpsv.cz/documents/20142/577769/NSRSS.pdf</u>
 ⁵⁴ The document is available online in Czech at: <u>https://www.mpsv.cz/-/vlada-schvalila-akcni-plan-k-prechodu-socialnich-sluzeb-na-komunitni-peci-cilem-je-zkvalitnit-zivot-klientum</u>

⁵⁵ The document is available online in Czech and English at: <u>https://vlada.gov.cz/cz/ppov/vvozp/dokumenty/narodni-plan-podpory-rovnych-prilezitosti-pro-osoby-se-</u> zdravotnim-postizenim-na-obdobi-2021 2025-183042/

⁵⁶ The document is available online in Czech at:

https://vlada.gov.cz/cz/ppov/vvozp/dokumenty/systemova-opatreni-pro-podporu-osob-s-intelektovym-znevyhodnenim-a-chovanim-narocnym-na-peci-na-obdobi-2024_2030-214216/

⁵⁷ We do not list homes for elderly people and respite services providers in this overview.

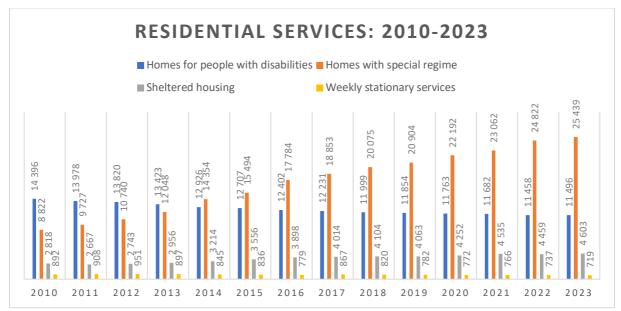
63. The Czech Ministry of Social Affairs reported that in 2023, there were 11 496 places in *residential homes for people with disabilities*, as many as 25 493 places in *special regimes residential homes*, 4603 places in *sheltered housing* and 719 places in *weekday residential care services*. In total, there were 42,257 places in these residential services housing people with disabilities.

Year	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Residential homes for people with disabilities	14 396	13 978	13 820	13 423	12 926	12 707	12 402	12 231	11 999	11 854	11 763	11 682	11 458	11 496
Special regime residential homes	8 822	9 727	10 740	12 048	14 354	15 494	17 784	18 853	20 075	20 904	22 192	23 062	24 822	25 439
Sheltered housing	2 818	2 667	2 743	2 956	3 214	3 556	3 898	4 014	4 104	4 063	4 252	4 535	4 459	4 603
Weekday residential care services	892	908	951	897	845	836	779	867	820	782	772	766	737	719

Table no. 1: Development of residential social care services between 2010 and 2023

Source: Ministry of Social Affairs, Statistical Yearbooks, 2010-2023

64. Graph no. 1 shows that since 2010 when the Czech Republic ratified the CRPD, the capacity of *residential homes for people with disabilities* has decreased from 14,396 in 2010 to 11,496 in 2023 (minus 2900 beds). In the same period, the capacity of *sheltered housing* increased from 2,818 places to 4,568 places (plus 1785 beds). At the same time, there is an extreme increase of places in *special regime residential homes*, from 8,822 places in 2010 to 25,439 places in 2023 (plus 16,617 places). There is also a decrease in the capacity of weekly stationary services (minus 173 beds).



Graph no. 1: Graphic overview of the development of residential social care services between 2010 and 2022

65. Further, it is apparent from the statistics that *residential homes for people with disabilities*, as well as *special regime residential homes*, are usually large-capacity

institutions. In 2022, their average capacity exceeded 50 beds. The facilities with the largest capacities are those maintained by the state directly or by the regions or local municipalities (see below Table No. 2). Residential homes for people with disabilities and special regime residential homes, two types of institutional settings, represent the cornerstone of the whole system.

	State facilities	Regional facilities	Municipal facilities	Church facilities	Other facilities	Total Average
Facilities for persons with disabilities	125,4	63,4	37,2	21,5	24,3	55,1
Special regime facilities	0	62,7	61,1	28	69,4	62,7

Table no. 2: Average capacity of social care facilities by provider in 2022

Source: Ministry of Social Affairs, Statistical Yearbooks, 2010-2023⁵⁸

3.3. Smaller residential services are unavailable and inaccessible

- 66. The so-called *sheltered housing* is considered both by the state and regional social policy to be the backbone of deinstitutionalisation and an ideal outcome of the transformation processes. Over the past decade, the state consistently presented the decrease in the capacity of residential homes and the increase in the capacity of sheltered housing as a formula and a showcase of deinstitutionalisation policy. Data showing that in over a decade, the capacity of *sheltered housing* increased from 2,818 to 4,568 beds is meant to confirm this supposedly positive policy trend. However, there are **three** problems.
- 67. *First*, there is a significant **unavailability of sheltered housing providers**, and the **increase of their capacity is very slow**. In 2023, there were only 4603 beds available in sheltered housing, compared to 11 496 in homes for people with disabilities and 25 439 in homes with special regimes. Thus, sheltered housing services represent only 11% of the whole residential care capacity. Moreover, **the development of sheltered housing across the country has been very slow** and **does not correspond to the demand and needs** of persons with disabilities. In 13 years, the State increased the availability of only 1785 beds. This corresponds to an increase of approximately 150 places yearly, while the demand and the need are much higher. In 2022, these services could not support as many as 2375 individuals due to limited capacity.⁵⁹ In 2023, the number increased to as many as 2447 individuals with disabilities who stayed without the service support.⁶⁰ In total, sheltered housing providers could not offer services to as many individuals as corresponded to more than ½ of their total capacity.

https://www.mpsv.cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci

⁵⁹ Ministry of Social Affairs, Statistical Yearbook, 2022, table 6.7. Available in Czech at: <u>https://www.mpsv.cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci</u>

⁵⁸ Data taken from the Statistical Yearbook of Labour and Social Affairs for 2022, table 6.5. The Statistical Yearbook is available in Czech at:

⁶⁰ Ministry of Social Affairs, Statistical Yearbook, 2023, table 6.7. Available in Czech at: <u>https://www.mpsv.cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci</u>

It is necessary to note that this number concerns only those who filed a formal request but were unsatisfied. There will be thousands – the precise number is very difficult to estimate – who have not made any formal

- 68. Second, three in four of the sheltered housing services do not meet simple criteria of everyday living, such as ensuring that adults with disabilities occupy a private bedroom. An independent study from 2021 shows that only 1250 places are located in a maximum of 3 persons households. Other 1188 places are in 4 to 6 persons households and 866 even in households with 7 or more members. Moreover, according to this study, only 1057⁶¹ places in sheltered housing services are offered as single bedrooms.⁶² In other words, many people living in sheltered housing must cohabit in one room with another person or, in some instances, even two other persons. However, enjoying a single room should be the minimum acceptable requirement for decent adult co-housing. The study noted, in this regard, that "a prerequisite for residential social services clients' lives to be as similar as possible to normal life is also whether they have their own room (bedroom) or are forced to share a bedroom with other service users".⁶³ In many instances, this is not the case in sheltered housing in the Czech Republic.
- 69. *Third*, the 2021 study points to a **particularly grave concern regarding the availability** and **accessibility** of sheltered housing services to **people with high-level needs**. Only 28% of clients in sheltered housing were classified as recipients of care allowances at the III and IV levels (people with high-level needs). Two-thirds were recipients of care allowances at the II and I levels (people with how-level needs).⁶⁴ This situation raises a problem of discrimination against people with high-level needs, such as people with autism, intellectual disability and challenging behaviour (see, below, paras. 107-117).
- 70. Moreover, there is also a problem of **territorial accessibility**. The study shows that the distribution of places in those service providers that can be characterised as community-based does not reflect the number of people in communities of a given size. For example, in large cities with more than 50,000 inhabitants, 30% of all people with intellectual disabilities live, but only 20% of the places in community-type facilities are available there. In large cities, there are 14 people with intellectual disabilities (not counting those with mild intellectual disabilities) per 1 place in community-based services. In contrast, for smaller cities, where the most places in such services are located, there are six people with intellectual disabilities per 1 place.⁶⁵

3.4. The unavailability and inaccessibility concern outreach social services designed to ensure independent living

71. For people with disabilities, *personal assistance services* (Article 39) and *support of independent living* (Article 43) represent crucial alternatives to residential services. These services have been introduced to national legislation to provide support to

request due to the unavailability of social services. Thus, the number of de fact unsatisfied persons and families is very likely much higher.

⁶¹ However, only 59% of service providers answered the question about the number of beds in a room and the total number of single rooms can be much lower.

⁶² Klusáček, J., Adamcová, M. Žít jako ostatní [Live like the others]. Prague: JDI & SPMP, 2021, p. 8.

⁶³ *Ibid*, p. 22.

⁶⁴ *Ibid*, p. 27.

⁶⁵ Ibid, p. 23 and p. 25.

people with disabilities living at home, enabling them to live as independently as possible.

	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Personal assistance	5228	5677	6554	7182	7835	8501	8979	8743	9716	10 123	10 191	10 083	10454	11172
Support of independent living	243	404	578	585	734	832	938	875	1112	985	1007	1041	1076	1113

Table no. 3: Users of outreach social care services: 2010-2023⁶⁶

- 72. According to data, the number of *personal assistance* users more than doubled between 2010 and 2023, rising from 5228 to 11 172 (personal assistance services support 5944 users more than 13 years ago). At first glance, this increase seems significant; however, four points need to be made.
- 73. *First*, the number of users has been almost stagnant over the last five years, while the number of residential services, including non-community services, has increased significantly. Between 2010 and 2015, the increase was 3273 personal assistance users, while the increase between 2018 and 2023 was only 1456 users. Between 2018 and 2023, the capacity of residential homes for people with disabilities decreased by approximately 500 beds. This decrease was compensated by roughly the same increase of places in sheltered housing, yet the capacity of homes with special regimes increased by an incredible 5364 places (see above para. 63 and Table no. 1). The data thus shows that the increase in availability of relevant outreach social care services is much unfavourable compared to those of residential facilities, which, for the most part, can be characterised as institutions.
- 74. Second, there is a significant regional variation in capacity. In the Prague region, in 2023, there were 2682 users of personal assistance services; however, for example, in the Karlovy Vary Region, there were only 156 users,⁶⁷ in the Pilsen Region, 203 users⁶⁸, in Vysočina Region, 223 users⁶⁹ and in the Olomouc Region 340 users⁷⁰. This variation is likely to reflect systemic underdevelopment of service capacity rather than differences in demand since the prevalence of disability (measured as the number of disability allowance direct payments in the population) is similar across all regions, ranging between 3,1 and 3,5 % only with Prague, paradoxically, registering the lowest

⁶⁶ Ministry of Social Affairs, Statistical Yearbooks, 2010-2023.

⁶⁷ Prague is a much larger region, with approximately 1 275 406 inhabitants in 2022, while in Karlovy Vary, there were 253 210 inhabitants. The ratio is thus 6:1. However, the ratio concerning the number of clients of personal assistance is more than 16:1.

⁶⁸ In 2022, the Pilsen Region had 578,707 inhabitants. The ratio of the number of users of personal assistantance services, compared to Prague, is highly disproportional. While the ratio concerning the number of inhabitants is 2:2, the ratio concerning users of personal assistance services is more than 13:1.

⁶⁹ In 2022, in the Vysočina Region, there were 504,025 inhabitants. The ratio is slightly lower than in the Pilsen region (see footnote above).

⁷⁰ In 2022, in the Olomouc Region, there were 634,718 inhabitants. Compared to Prague, it is thus approximately 2:1. However, the ratio concerning the number of users of personal assistant services is almost 8:1. Another region, namely the South-Bohemian Region, is almost identically large in terms of the number of inhabitants as the Olomouc Region, yet, there were in 2023 579 users of personal assistance services, thus significantly more comparing to the Olomouc Region.

proportion of people with disabilities in population nationwide (2 %) while having number of personal assistance users by more than a tenfold. These data prove extreme regional disparities. Consequently, there is an issue of limited access to personal assistance services in various regions.

- 75. *Third*, the systemic disadvantage of outreach social care services is also evident in the data on the public funding of social services. Data collected by the Ministry of Social Affairs prove that **residential social care services**, **largely non-community-based**, **have been favoured in terms of public funding over outreach services**.⁷¹ At the outset, it is to be noted that the official statistics of the Ministry of Social Affairs do not offer directly comparable data since the categories of information relating to funding of services differ between residential services and ambulatory or outreach services. Nevertheless, essential observations can still be deduced, proving **the concern of the distribution of available resources**.
- 76. The data show that the financial support for residential social care services has increased significantly more dynamically than outreach and day services, even in recent years. Between 2011⁷² and 2023, the direct state subsidies on homes with people with disabilities grew by approximately CZK 2.5 billion (EUR 100 mil), and on homes with special regimes by approximately CZE 5 billion (EUR 200 mil). Between 2018⁷³ and 2023, the direct state subsidies for sheltered housing grew by approximately CZE 500 mil (EUR 20 mil). In comparison, the expenses on personal assistance grew between 2011 and 2023 by only approximately CZK 1.46 billion (EUR 58.5 mil), and the expenditures on support for independent living grew between 2011 and 2023 by approximately CZK 150 mil (EUR 6 mil).
- 77. Direct public expenditures on two crucial outreach services grew by roughly EUR 65 mil over 12 years. At the same time, direct public spending on two typically non-community-based residential services grew by approximately EUR 300 mil. Thus, the ratio is roughly below 4.6:1 in favour of residential settings. By including sheltered housing, which—as argued above (see para. 68 above) cannot be automatically considered a community-based service—the ratio would be 5:1 in favour of residential settings.
- 78. Further, this ratio has not been changing over time. In 2011, the direct public expenditure on two residential services (homes for people with disabilities and homes with special regimes) was approximately CZK 2.5 billion (EUR 100 mil). The expenses for personal assistance and support of independent living were approximately CZK 360 mil (EUR 14.4 mil). In 2023, the combined direct public expenditure on homes for people with disabilities and homes with special regimes was approximately CZK 10 billion (EUR 400 mil), while the expenses on personal assistance and support of independent living were approximately CZK 200 mil (EUR 400 mil). The expenses on personal assistance and support of independent living were approximately CZK 200 mil (EUR 80 mil). Over twelve years,

⁷¹ Data taken from the Statistical Yearbooks of the Ministry of Social Affairs. The yearbooks are available in Czech at: <u>https://www.mpsv.cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci</u>

⁷² We make the comparison since 2011 because this is the first year when the Government started explicitly collect data on the extent of state subsidies to residential social services.

⁷³ This is the first year the Government started explicitly referring to data concerning direct state subsidies for sheltered housing.

it has been apparent that the ratio remains stable at 5:1 in favour of largely non-community-based residential services.

- 79. Considering this, the existing data proves not only that the **residential social care** services, largely non-community-based, have been favoured in terms of public funding over outreach services in absolute spending but also that the level of spending has not changed in favour of outreach, as well as non-institutional social care services. It, thus, cannot be said that the Czech Republic complied with the criteria set by the Committee concerning Article 14§1 of the Charter, namely, to take action in terms of financing consistent with the maximum use of available resources.⁷⁴
- 80. Regarding the second type of outreach support for people with a disability, called *support of independent living*, it is apparent that in 2023, there were only 1113 users of this community-based service in the whole country. Strikingly, in two regions (out of 14), there was not a single user, and this type of service was **entirely unavailable**, namely in Karlovy Vary region and Ústí region. In the other three regions, this community-based service **was hardly available**. In the Vysočina region, there were only four users; in the South Bohemia region, there were ten users, and in the South Moravia region, there were 14 users. On the other side, the highest number of users was in Prague region (133), Liberec region (233) and Moravia Silesia region (336).⁷⁵ Similar to personal assistance, support of independent loving also showed **extreme regional disparities**. It raises **serious concerns about the availability and accessibility** of this type of crucial community-based service for people with disabilities in the Czech Republic.

3.5. The State Party has failed to allocate adequate resources and distribute them efficiently

- 81. In 2023, the Ombudsperson published a research report on the current situation concerning the implementation of Article 19 CRPD and the obligation to ensure independent living for people with disabilities. The report highlights several structural deficiencies concerning deinstitutionalisation and the social services system.⁷⁶ A key concern was the failure to provide adequate funding for social services. The Ombudsperson found a systemic failure to efficiently distribute available resources to finance social services, including efficient funding of deinstitutionalisation. The Ombudsperson named three funding-specific issues.
- 82. The *first* issue concerned **the distribution of resources required to ensure deinstitutionalisation**. The transformation of residential services involves many financially demanding activities, such as renovating buildings, investing in equipment

⁷⁴ ECSR, *International Federation of Human Rights (FIDH) v. Belgium*, complaint no. 75/2011, decision on the merits of 18 March 2013, § 145.

⁷⁵ Ministry of Social Affairs, Statistical Yearbook, 2023, table 5.4. Available in Czech at: <u>https://www.mpsv.cz/statisticka-rocenka-z-oblasti-prace-a-socialnich-veci</u>

⁷⁶ Czech Ombudsperson Research Report. *Deinstitucionalizace a transformace sociálních služeb – přístup krajů a Ministerstva práce a sociálních věcí ve strategických dokumentech* [Deinstitutionalisation and transformation of social services - the approach of regions and the Ministry of Labour and Social Affairs in strategic documents]. Brno, 2023. The report is available in Czech at:

https://www.ochrance.cz/projekty/posileni-aktivit/deinstitucionalizace a transformace socialnich sluzeb.pdf

and facilities, etc. However, several regional authorities complained to the Ombudsperson that the lack of investment funds hinders the implementation of planned transformations. Many social services transformation projects require more funding than the regions have available from the state. As a result, some regions were forced to decide whether to reduce investment or extend investment plans over several decades.⁷⁷ One of the regional government representatives noted:

"So I think, we chose that strategy at the beginning, that let's proceed to transform what is quite clearly obsolete. And let's leave that here for now because it's going to take a while. Because I really don't think it's even within the power of the region for me to make all those investments. If we wanted to flip everything now into something like ten years, I don't think even investment-wise the region is able to accommodate that because they have other investments."⁷⁸

- 83. The financing comes from multiple sources, typically the EU funds and EU resilience plan, supplemented by funds from the state or regional budgets, which, according to the Ombudsperson, has a negative impact. Namely, the Ombudsperson reported that "the current form of multi-source financing may have a negative impact on the progress and implementation of projects. Due to the changing conditions of individual calls, regions may face the risk of losing funds they have already invested in the preparation of grant projects."⁷⁹
- 84. Second, sustaining the operation of transformed services also proved problematic due to underinvestment in services. According to several regions, as reported by the Ombudsperson, the operation of community-oriented social services requires increased financial costs. However, the unavailability of funding for the future operation of transformed services impedes transformation. As a result of this uncertainty, the preference might be to modify and maintain existing institutional services rather than to transform them fully. One regional government representative explained in this regard:

"Then, of course, I'm struggling with the fact that the creation of these new transformed facilities is much more expensive, and that's why (...) they don't even go for it, they try to improve the existing environments a little bit, but would not go for a full transformation, ... because they are not granted the resources for the normal operation afterwards."⁸⁰

85. According to some regions, the system of financing social services does not reflect that some transformed services can be more financially demanding. State funding for services remains at the same level as for institutional social services, even though transforming the institutional model of care into a community-based one is one of the fundamental pillars of state policies. In other words, a region that meets these commitments and transforms services receives the same amount of money to provide them as before the transformation.⁸¹

⁷⁷ *Ibid*, p. 81.

⁷⁸ Ibid

⁷⁹ *Ibid*, p. 82.

⁸⁰ *Ibid*.

⁸¹ Ibid.

86. *Third*, the funding mechanism has been described as "unsystemic", raising "a serious problem" in practice "affecting the ability to plan and deliver the necessary social services".⁸² The Ombudsperson identified two sources of weakness. First, the economic situation of the Czech Republic in 2023, particularly the constraints associated with austerity measures, which create uncertainty about investments in the development of services, including the transformation process. The second concern is structural and long-lasting. It is the one-year financing system for social services, which, according to the Ombudsperson report, generates uncertainty with every budget and "complicates medium-term planning necessary for the development of services", concerning the whole system of social services and results in "limited room for manoeuvre in service development and deinstitutionalisation". One of the regional government representatives, interviewed by the Ombudsperson, summed up the situation as follows:

"This is how we really live from year to year. We are always praying what allocation will come. Even though the allocation is increasing in the state budget, with the percentages to the regions, it does not correspond to reality then. That drop we have is about 500 million a year, and of course, those services, first and foremost, pay for those ongoing operations. So people get paid, operating costs get paid, but **little or nothing is left for capacity development**."⁸³

87. Thus, it was reported by the regional authorities⁸⁴ that the Central Government, namely the Ministry of Social Affairs, failed to "clearly defined framework conditions for financing, which leads to uncertainty in obtaining funding for the provision of [social] services".⁸⁵ As a result, in the whole system, according to the Ombudsperson report, there is uncertainty having a negative impact on social service planning and capacity development. The Ombudsperson quoted a regional government representative stating that:

"Of course, the big problem is the unsystematic financing of the whole social services segment."⁸⁶

88. The Ombudsperson further concluded that **the unpredictable funding, which is the responsibility of the Ministry of Social Affairs, creates a gap between needs and available funds**. The problem concerns the lack of knowledge on the side of the regional authorities on how much they can spend and invest and in what services in particular. As the Ombudsperson concluded that it can, therefore, be

"inferred that the unsystematicity lies in the lack of linkages between financial allocation and service development. This barrier hinders the effective planning and development of social services. The limited ability to plan with a clear view of the available financial resources puts social service providers in a difficult situation".⁸⁷

⁸² *Ibid*, p. 97.

⁸³ *Ibid,* p. 83.

⁸⁴ Under Article 95(d) of the Social Services Act, the Region must develop a mid-term plan for developing social services within its territory.

⁸⁵ Ibid, 97.

⁸⁶ Ibid, 97.

⁸⁷ Ibid.

3.6. The State Party has failed to plan social care services adequately: failure of proper DEI planning

- 89. The problems with financing described above must be understood in connection with the so-called planning and commissioning of social services. As described above, the government and regions are legally obligated to plan and commission social services (see paras 56-57 above). Concerning this obligation on national and regional level, we identify, following the Ombudsperson and independent research, **two interlinked problems**: *First*, the **transformation from institutional settings to community-based social care services has not been adequately planned**, which is the failure to plan DEI appropriately (subsection 3.6.). *Second*, in the State Party, **there is a failure to properly plan for commissioning new social care services**, which concerns the general planning of social care services (subsection 3.7.).
- 90. At the outset, it must be noted that the Social Services Act does not explicitly contain an explicit obligation to deinstitutionalise residential social care. Moreover, the law does not ban the establishment of new residential social care services above a particular capacity or impose a capacity limit. In general terms, Article 2 of the Social Services Act provides that priority is given to those social care services that "support the person's stay in his or her natural social environment". The commitment to transform residential social care services, in line with the 1961 Charter and Article 19 CRPD, can be found in Government policy documents and some regional policy documents. However, research and the Ombudsperson agreed that Government policy documents suffer from contradictions and unclarity.
- 91. Already, the very first Government policy document on deinstitutionalisation, the socalled *Concept Document for Supporting Transformation* adopted in 2007, announced a move away from institutional care but at the same time proposed building residential facilities with a capacity of up to 40 persons. Current Government policy documents, namely the 2016-2025 National Strategy of the Development of Social Care Services and the 2023-2025 Action Plan for transitioning social services to community-based care, are still based on the same logic. Smaller residential providers should replace large residential service providers. In other words, **Czech policies on social care aim to develop only smaller residential social care services and plan only lowering number of beds in large residential services and increasing number of beds in smaller residential services. According to the independent research:**

"If the Action Plan reduces deinstitutionalisation to a transition from institutional residential services to community-based residential services, then what it is primarily concerned with is the planning of *residential services*. And such planning is characterised by the logic of the number of 'beds' and the number of 'facilities'. In 'non-community' facilities, the number of beds needs to be reduced, while in community residential services, which are still generally 'low in number', the number of beds needs to be increased. It is only the number of facilities and the number of beds in residential services that can be planned, not the capacity for individualised support in e.g. outreach services."⁸⁸

- 92. Consequently, "[t]he alternative of outreach individualised care and support (and, in the case of clients with complex needs, individualised multidisciplinary and coordinated care) does not seem to be at all on the horizon of strategic thinking about the need to change from residential to community care".⁸⁹ Strikingly, even though the National Strategy and the Action Plan repeatedly refer to developing outreach services, yet despite proclamations, neither the National Strategy nor the Action Plan "contain a single measure that would actually lead to the development of outreach services as an important alternative to institutional services".⁹⁰
- 93. Ombudsperson, in his 2023 report, made similar findings. He studied the Governmental and regional policy documents against several criteria, including the clarity of objectives. In this regard, the Ombudsperson found that national and regional policy documents suffered from two fundamental shortcomings. First, they do not state these objectives at all, or they only vaguely set out the objectives. In concrete, only half of the regional policy documents contain strategic objectives focused on deinstitutionalisation (50%), and only about one-fifth of them focus on preventing institutionalisation (21%). As many as 13 out of 14 regional policy documents and the national policy document do not concentrate in their sub-objectives on preventing the transfer of institutional elements into new social care services. Second, the proclamation of the aim of deinstitutionalisation varies between the Ministry of Social Affairs and the regions and between regions themselves.⁹¹
- 94. The Ombudsperson further noted that this unclarity results from a systemic problem of social care services financing (paras. 81-88 above). The Ombudsperson identified these elements as having negative impact: (i) multi-source funding, (ii) the failure to ensure that the system of financing social services is linked to their development, and (iii) the unpredictability of the amount of funds that the regions receive for the development of social services through a subsidy from the Ministry of Social Affairs. According to the Ombudsperson, "it is difficult for regions to plan the use of maximum resources for the implementation of deinstitutionalisation due to the system of financing social services based on a one-year cycle. Although we consider the particular strategy documents of the regions aimed at deinstitutionalisation as good practice⁹², the obstacles caused by the system of financing services also affect the possibility of fulfilling them."⁹³

⁸⁸ Paleček, J., Kocman, D., Valinová, L. Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Prague: Abakus, 2024, p. 61.

⁹⁰ Ibid

⁹¹ Czech Ombudsperson Research Report. *Deinstitucionalizace a transformace sociálních služeb – přístup krajů a Ministerstva práce a sociálních věcí ve strategických dokumentech* [Deinstitutionalisation and transformation of social services - the approach of regions and the Ministry of Labour and Social Affairs in strategic documents]. Brno, 2023, p. 106-107.

⁹² Some regions have adopted special policy documents, yet the fulfilment is problematic.

⁹³ Czech Ombudsperson Research Report. *Deinstitucionalizace a transformace sociálních služeb – přístup krajů a Ministerstva práce a sociálních věcí ve strategických dokumentech* [Deinstitutionalisation and transformation of

3.7. The State Party has failed to adequately plan social care services: failure of proper commissioning of social services

- 95. The inappropriate commissioning of social services in the Czech Republic raises another issue under the 1961 Charter. The law obliges public authorities to plan the development of social services. Under Article 95(d) of the Social Services Act, the regional authority must adopt a mid-term plan for developing social services within its territory. The legal obligation to plan social services represents a crucial instrument in progressive implementing obligations stemming from the 1961 Charter.
- 96. Three problems regarding social services planning can be identified based on expert reports, namely the 2023 Ombudsperson report and the 2024 independent research report.
- 97. *First*, the structure and volume of regional social service capacity do not meet the needs of people with disabilities. And the **commissioning failure**, according to the Ombudsperson report, starts with **serious issues in strategic needs assessment**. The Ombudsperson report identified it as one of the key barriers in the commissioning process. It was reported that "[t]he lack of detailed information on needs in the regions complicates planning and **may result in some potential clients being excluded from the social care system**."⁹⁴ The Ombudsperson stated that the Ministry of Social Affairs admitted that "there are significant differences in the collection of information on needs between regions. This problem is evident not only in the planning process itself but also in the decision to include specific services and providers in the network."⁹⁵
- 98. Strikingly, the Ministry of Social Affairs Access further accepted that, consequently, the failed planning of social services by regions could significantly impact the availability and accessibility of social services to certain groups. Specifically, the Ministry of Social Affairs stated that there are "also [regional] differences in the approach to different user groups across regions, which may result in uneven coverage of services for some user groups."⁹⁶ As we argued above, precisely this is the case for people with high-level needs, such as people with autism, intellectual disability and challenging behaviour (see paras. 107-117 below). The Ministry of Social Affairs representative expressly stated that:

"(...) we must gather all our forces to set the same rules, the same conditions in all regions. (...) The point here is that we have to unify the rules (...) which is expected of us. We have to maintain a certain quality of life for users (...)"⁹⁷

99. Until now, **the Ministry of Social Affairs has taken no action**. This must be seen against the background of another persistent problem, namely "the low rate of

social services - the approach of regions and the Ministry of Labour and Social Affairs in strategic documents]. Brno, 2023, p. 107.

⁹⁴ *Ibid,* p. 96.

⁹⁵ *Ibid*, p. 97.

⁹⁶ Ibid

⁹⁷ *Ibid*, p. 97.

implementation" of strategic aims set by regional governments in their 3-year development plans, when "only part of the already weak pro-growth measures are implemented during the three-year plan".⁹⁸ Indeed, and this is the second problem, regional authorities legally responsible for ensuring that the regional service structure and capacity meet the needs of people with disabilities have been passive. This problem of insufficient capacity development is linked to the uncertainty concerning the financing of social services (see above) and the central government's failure to adopt adequate legal regulations, including rules that would enable the Ministry of Social Affairs to make the regions commission social services appropriately.

- 100.Independent research has reported that in developing the capacity of social services, regions rely on passive commissioning tools such as opening calls for providers to submit proposals to increase their capacity within the existing social services network in a concrete region. Overreliance on this market mechanism stems from an assumption that enough bidders eager to compete for resources under present terms and conditions will allow the commissioners to select the best ones. However, reality has proven such an assumption a fantasy. It has shown that all regions face capacity shortages, provider cherry-picking, insufficient support in new service development and generally an environment more akin to natural monopolies with limited competition than true markets. Passively calling for tenders and waiting to select the best social service providers has proved inappropriate for a social services development able to meet the needs of people with disabilities. Instead, the regions should assume full responsibility and activity in all stages of the commissioning cycle.
- 101.To quote from the report: "[r]egions lack instruments to support and motivate development across the service network, especially those that would allow financing of the preparatory phases of new services ..., and they lack a culture of proactive demand and negotiation for development", noted the research.⁹⁹ Therefore, in concrete regional plans¹⁰⁰, "one can rather read that the region plans to discuss the submitted proposals of social service providers", and among the risks the region sees "in the first place the lack of interest of social service providers".¹⁰¹ Thus, "[y]ear after year, the regions have shrugged their shoulders at the fact that no one has signed up to the calls for development."¹⁰² In other words, "[i]nstead of planning development according to needs [of people with disabilities], actively demanding and robustly supporting the creation of new capacity, the regions are positioned in a passive waiting role."103

⁹⁸ Paleček, J., Kocman, D., Valinová, L. Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Prague: Abakus, 2024, p. 87. ⁹⁹ *Ibid*, p. 88.

¹⁰⁰ The regions are obliged to draft concrete documents called mid-terms plans of development of social services. The content as well as the supervision is not regulated.

¹⁰¹ Paleček, J., Kocman, D., Valinová, L. Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Prague: Abakus, 2024, p. 88. ¹⁰² *Ibid*.

¹⁰³ *Ibid*.

- 102. The *third* problem concerns the failure to ensure meaningful participation of people with disabilities and informal caregivers in social services commissioning. As the Ombudsperson specified, this problem has two levels: *national* and *regional*.
- 103. On the *national level*, the Ombudsperson found that within the policy-making process, namely, as part of drafting the national plan for developing social care services (see above para. 57), people with disabilities took no direct part. Only organisations of people with disabilities were involved. However, "these organisations had no representation in the steering group and were only represented in the working groups by only four out of the forty-eight participants".¹⁰⁴ Admittedly, lower representation does not necessarily indicate a failure to comply with the principle of participation. However, the national plan, as the Ombudsperson noted, "does not indicate in what specific way the views of organisations advocating the rights of people with disabilities were taken into account, or to what extent their voice played a fundamental or determining role in the principle of participation was at least formally fulfilled in drafting the National Policy".¹⁰⁵
- 104.On the *regional level*, under Article 95(d) of the Social Services Act, the regions have a statutory duty to co-produce strategic planning of social services in cooperation with local municipalities, social services providers and people with disabilities. In other words, there is a legal obligation to ensure the participation of people with disabilities in planning, including people with autism, intellectual disability and challenging behaviour. However, the Ombudsperson found that "all regions cooperate in developing the regional plans with municipalities and social care providers". While all strategic documents refer to the participation of people with disabilities, there is no "information on the type of disability".¹⁰⁶ Out of 14 regions in the Czech Republic, "only one region explicitly mentioned the involvement of people with intellectual disabilities and mental illness."¹⁰⁷
- 105. Further, many regions consider a public consultation once strategic documents are drafted as participation. However, public consultation after the process does not meet the criteria of genuine co-production and involvement in the commissioning process as a whole. Moreover, it was found that "the involvement of organisations defending the interests of people with disabilities is very low, mentioned by only two regions." In contrast, eleven regions declare the involvement of caregivers. The Ombudsperson critically noted that local municipalities, service providers and caregivers can emphasise different aspects of the development of social services. Hence, the "overall higher representation of municipalities, service providers or caregivers may lead to a further weakening of the voice of people with disabilities. Thus, even the regional plans do not fully meet the principle of participation."¹⁰⁸

¹⁰⁴ Czech Ombudsperson Research Report. Deinstitucionalizace a transformace sociálních služeb – přístup krajů a Ministerstva práce a sociálních věcí ve strategických dokumentech [Deinstitutionalisation and transformation of social services - the approach of regions and the Ministry of Labour and Social Affairs in strategic documents]. Brno, 2023, p. 56.

¹⁰⁵ *Ibid*.

¹⁰⁶ Ibid.

¹⁰⁷ *Ibid*.

¹⁰⁸ *Ibid,* p. 57.

106. The failure to include the voices of people with disabilities, including people with autism, intellectual disability and challenging behaviour, in the planning and commissioning process affects not only the transparency of the whole process in the Czech Republic but significantly results in a distorted picture of needs. **Considering this, we argue that the situation in the Czech Republic is not in conformity with Article 14§1 and Article 14§2 of the 1961 Charter, read separately and in conjunction, which provides for the right to participation of people with disabilities.**

3.8. People with high-level needs are primary victims of the absence of appropriate social care services

- 107.The data presented above, as well as the expert reports, show that over the past decade, the number of places in large residential services for people with disabilities has slowly decreased. However, according to experts, there is a low supply of community services,¹⁰⁹ both residential and outreach services (see subchapters 3.3.-3.4.). The insufficient supply of community services, especially outreach services, prevents, according to expert reports, people with disabilities, and especially people with high-level needs, from choosing an appropriate service, thus preventing them from making free decisions about their lives.¹¹⁰
- 108.It has been reported that especially people with higher levels of support needs and intellectual disabilities **face a greater risk of being institutionalised**.¹¹¹ Currently, such people occupy 81 % of places in one of the most common, and typically institutional, residential service providers, *homes for people with disabilities*.¹¹² In this regard, one study scores the Czech Republic worse overall than the European average (with a score of 4.3, the average being 5.0 out of 10) and significantly worse than the European average in the domains relating to the implementation of the right to independent living, i.e. transformation and supported living in the community. The Czech Republic performs significantly below average in both domains compared to European countries (2.8 out of 10 and 1.8 out of 10, respectively).¹¹³
- 109. Indeed, the data shows that currently, over 11,000 people use personal assistance and support for independent living. At first glance, it looks like a significant increase

¹⁰⁹ See, in English, e.g. Šiška, J. a Čáslava, P. 2021. Towards Community-based support services in Czechia: nearly there? In. Šiška, J. et al. *The Development, Conceptualisation and Implementation of Quality in Disability Support Services*. Prague: Karolinum, 123–134; Recent Czech report is Kocman, D., Paleček, J., Valinová, L. *Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR*. [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Abakus, 2024, p. 27-29. The report is available at:

https://abakus.cz/file/ke-stazeni/Stale na zacatku Zprava o stavu socialni politiky a sluzeb v CR.pdf¹¹⁰ *Ibid*.

¹¹¹ Kocman, D., Paleček, J., Valinová, L. *Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR*. [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Abakus, 2024, p. 27.

¹¹² Klusáček, J., Adamcová, M. Žít jako ostatní [Live like the others]. Prague: JDI & SPMP, 2021, p. 27.

¹¹³ Inclusion Europe 2023. Inclusion indicators 2023: Rights and inclusion of people with intellectual disabilities in 29 European countries. Brussels: Inclusion Europe. Available at: <u>https://www.inclusion.eu/indicators</u>

compared to 2010. However, as reported by independent research, the data also show a very worrying trend. Nominally, there are more users of this crucial community service. Yet, when the volume of support provided is calculated per user, **it remains virtually unchanged in the long term, and its value is very low**. If in 2009, the average number of minutes per client per day was about 27 minutes for support for independent living, in 2022, it was even lower: 14 minutes. For personal assistance, the average is still around half an hour, and in 2009, as in 2022, it is rounded to 32 minutes. It follows from this data that **the ability of outreach services to ensure support to people with high-level needs has not been improving**, even though they sometimes prefer this type of social care service over residential services.¹¹⁴ In other words, **personal assistance and support for independent living are inaccessible to people with high-level needs who require higher-intensity personalised support**.

- 110.Unfortunately, the overall problem can be demonstrated by a specific phenomenon that raises issues under Articles 11§1 and 11§3 of the 1961 Charter. Namely, the unnecessary and prolonged psychiatric hospitalisations of people with specific high-level needs, namely people with autism, intellectual disability and challenging behaviour. It is striking that this phenomenon concerns especially children with autism.
- 111. After long calling on the Government by the NGOs and organisations of carers to start taking at least some action in this regard, in 2024, the Government adopted a strategy called *Systemic measures to support people with intellectual and challenging behaviour for the period 2024-2030*.¹¹⁵ The document calls on the Government to take urgent action, especially the Ministry of Social Affairs,¹¹⁶ noting the alarming situation that, among other things, "more than 200 people from this group are on long-term placements in an inadequate environment of psychiatric hospitals"¹¹⁷ The document expressly recognises that:

"Due to a lack of capacity and expertise in positive behaviour support, many people with challenging behaviour are forced to live in psychiatric hospitals for long periods of time. This practice represents a serious interference with their rights and a significant risk to their health. Similarly inappropriate is the placement of these people in high-capacity residential social services, which,

¹¹⁴ Kocman, D., Paleček, J., Valinová, L. *Stále na začátku. Zpráva o stavu sociální politiky a sociálních služeb ve vztahu k naplňování práva na nezávislý způsob života lidí se zdravotním znevýhodněním v ČR*. [Still at the beginning. Report on the state of social policy and social services in relation to the fulfilment of the right to independent living for people with disabilities in the Czech Republic]. Abakus, 2024, p. 43.

¹¹⁵ The Government adopted the document on 26 June 2024. The press-release is available in Czech at: <u>https://vlada.gov.cz/cz/ppov/vvozp/dokumenty/systemova-opatreni-pro-podporu-osob-s-intelektovym-znevyhodnenim-a-chovanim-narocnym-na-peci-na-obdobi-2024_2030-214216/</u>

¹¹⁶ Problematically, **the adopted strategy is not binding**. It contains generally formulated measures, such as "[t]o provide people with challenging behaviour currently in long-term psychiatric hospitals and living in residential social services facilities of an institutional type with an appropriate community-based residential or outreach service" (p. 31). Moreover, **it fails to set concrete deadlines** and **allocate responsibility for overseeing**. Overall, the document is rather a description of the situation than an efficient policy document.

¹¹⁷ Systemic measures to support people with intellectual and challenging behaviour for the period 2024-2030, p.
6. The document is available online in Czech at:

https://vlada.gov.cz/assets/ppov/vvozp/dokumenty/Systemova-opatreni-pro-podporu-osob-s-intelektovymznevyhodnenim-a-chovanim-narocnym-na-peci.pdf

according to the available evidence, worsens their quality of life and increases the risk of escalation of challenging behaviour."¹¹⁸

112.In this regard, the Government's Human Rights Commissioner, Ms Šimáčková-Laurenčíková described the actual situation in the Czech Republic as follows:

"There is currently a noticeable lack of services for people with intellectual disabilities and challenging behaviour in the country. Existing services are at full capacity for years to come. Some of these people are currently ending up in psychiatric wards in hospitals when they do not belong there at all. Unfortunately, the current system also still tolerates the use of restrictive, unacceptable practices. That is why we need to effectively put into practice modern practices that work abroad, such as positive behaviour support".¹¹⁹

- 113. The situation concerning the unwarranted psychiatric hospitalisation of people with autism, intellectual disability and challenging behaviour is not only a long-lasting problem in the Czech Republic, as the statements mentioned above prove, but **very urgent**. Strikingly, **it concerns children**. In October 2024, the Opařany Psychiatric Hospital, the Czech children's psychiatric institution, formally informed Ms Šimáčková-Laurenčíková, the Government's Human Rights Commissioner about the long-lasting unavailability of social services for children with disabilities. According to the hospital, the situation is alarming. The hospital named three concrete cases (emphasis in the original document):
 - "1. minor patient MR, year of birth 2010, Municipal district of Prague 5 ... the patient has been hospitalised for a long time since 12.10.2023, ready for discharge since February 2024, no social service provider found;
 - 2. minor patient RZ, year of birth 2007, Municipality of Votice ... patient repeatedly hospitalised since November 2023 and spent 205 days in DPNO. <u>Discharged on 8.8.2024 to the Fund for Children at Risk Žatec (vacancy negotiated by the Children's Psychiatric Hospital Opařany)</u> and awaiting placement in a suitable environment.
 - 3. minor patient JH, year of birth 2009, Mladá Boleslav Municipality ... The patient was hospitalised for 371 days since 22.8.2022. On 1.10.2024, he was discharged to the care of his parents and is waiting for the resolution of the social situation; the situation in the family is not manageable."
- 114. The first patient has been hospitalised unnecessarily for over a year and is still in the hospital due to the unavailability of social services in the community (see para. 121 below). The other two minors with autism, intellectual disabilities and challenging behaviour were hospitalised in an inappropriate environment for 205 and 371 days, respectively, only to be discharged to another inappropriate environment, be it an inappropriate childcare provider or resulting in an unsafe discharge to the home environment when the family was unable to ensure adequate care.
- 115. The unavailability and inaccessibility of social care services, especially communitybased care and the resulting extended psychiatric hospitalisations without any therapeutic purpose is further detailed by concrete stories of families of children with

¹¹⁸ *Ibid,* p. 31.

¹¹⁹ The press-release of the Czech Government published on 26 June 2024, available at: <u>https://vlada.gov.cz/cz/media-centrum/aktualne/osobam-s-intelektovym-znevyhodnenim-a-chovanim-narocnym-na-peci-se-zlepsi-pristup-ke-zdravotnimu--socialnimu-nebo-vzdelavacimu-systemu-214213/</u>

autism, intellectual disability and challenging behaviour. In 2024 and early 2025, FORUM collected actual stories of families (one of the stories concerns minor patient MR, mentioned above). These stories, described in more detail below from the perspective of the informal caregivers (see paras 119-122 below), prove that parents are forced to place their children with autism, intellectual disability and challenging behaviour in psychiatric hospitals due to the unavailability and inaccessibility of social care services. Moreover, it also shows, rather vividly, how deeply inadequate psychiatric hospitals can be for children with autism. Mrs F., a mother of a still minor child who has still been unnecessarily hospitalised in psychiatric hospital Prague Bohnice since February 2024, described in an interview on 4 November 2024 the moment of hospitalisation as follows:

"Once the class teacher was absent and he had some... that he pressed the assistant to the blackboard. I think he was nervous. Maybe he was bothered that the kids were yelling or something, that they were disturbing him there. And then they made me put him in the hospital in Bohnice. They said [the school] he was attacking people and that it couldn't be like that. Otherwise, they won't let him go back to school. **Hospitalization was their recommendation**. Although I didn't want to put him there because I didn't think it would help anyway. But I agreed. Because not even Dobromysl [respite service provided in the city where Mrs F lives] would give me services. **So, neither the respite service nor the school actually wanted to. So I was quite in a situation of helplessness**."¹²⁰

116.A horrific experience in a psychiatric hospital was described by Mr V., a single father of René, who is 19 at the moment. Mr V recalled his experience at the psychiatric hospital (the Moravian-Silesian Region), where he was forced to send his then-minor son René due to the complete unavailability of social care services in Zlín Region. In an interview on 20 November 2024, Mr V stated:

"The helplessness and the horror and the terror when I brought him to that [adult] ward, among those grown men [in psychiatric hospital Opava]. When I brought him in, I saw a big room where there were just tables and human wrecks sitting behind them, like men, maybe 50-60 years old. Everybody had a newspaper or a pile of tobacco in front of them and they were all rolling cigarettes. And there I was supposed to take a kid who was 14 or 15 years old. So I was afraid that somebody would abuse him, so I kept calling there."¹²¹

Mr V. further recalled:

"There [at the psychiatric hospital in Opava] **they were constantly restraining him.** He was restrained by a belt about twelve times, and he might even wet himself during the restrain; he couldn't go to the toilet. He was curtailed for six hours straight, ten hours straight. His hands were covered in blood from all the curtsies. He was also being beaten, which I have a testimony from a patient that Rene was talking to there. He had a mobile phone, so I was communicating with him via text message and he was saying - try to take him away, he's being beaten here. **They also gave him electroconvulsions and put**

¹²⁰ Statement from an interview with Mrs F, conducted by Ms Jolana Miličičová during the research on 4 November 2024.

¹²¹ Statement from an interview with Mr V, conducted by Ms Jolana Miličičová during the research on 20 November 2024.

him on so much medication that when René came back from Opava he was just crying, wearing diapers, wetting himself, drooling and walking all crooked. He didn't talk, he just lisped. He couldn't even drink, when he drank, it flowed. They made a complete wreck of him."¹²²

117.Considering the situation of the specific vulnerability of children with autism, intellectual disability and challenging behaviour, the whole phenomenon of psychiatric hospitalisations, so very typical in the Czech Republic, raises severe issues under the 1961 Charter, especially Articles 11§1 and 11§3 of the 1961 Charter and the prohibition of discrimination. Recently, in the judgment *V.I. v Moldova*, the ECtHR found that "placement in a psychiatric hospital and psychiatric treatment in the absence of any therapeutic purpose"¹²³ of a child with intellectual disability can raise issues under the prohibition of ill-treatment and discrimination. Indeed, similar to the case of *V.I.*, the placement of children referred here in psychiatric hospitals was caused by the absence of alternative care options. Consequently, the situation in the Czech Republic cannot be considered in conformity not only with Article 14§1 and Article 14§2 but also with Article 11§1 and Article 11§3 of the 1961 Charter and the prohibition of discrimination embedded in the 1961 Charter and especially in the Preamble.

3.9. Violation of rights of informal caregivers

- 118. In this collective complaint, we argue that the situation in the Czech Republic does not comply with caregivers' rights for two reasons. *First*, the shortage of care solutions and social services adapted to the needs of persons with high-level needs causes many families to live in precarious circumstances. *Second*, the State Party failed to develop an accessible network of respite services, significantly affecting families of children with high-level needs.
- 119.Concerning the first argument, we present several recent stories from different Czech regions, depicting different situations of caregivers and their families, which, however, have a common denominator the disastrous negative consequences of the absence of adequate support from the State Party concerning the unavailability and inaccessibility of social care services.¹²⁴ The first is the story of Mr P.V., whose quotes we cited above. Mr P. V. is a single father of a son with autism, intellectual disability and challenging behaviour from the Zlín Region.¹²⁵

The situation of Mr P.V.

The father, a 60-year-old single parent, faced immense challenges as the primary caregiver for his son René, who has autism, ADHD, moderate intellectual disability and challenging behaviour and had recently undergone thyroid cancer surgery. René's condition required lifelong, high intensity care and support due to his complex and permanent disabilities. Despite his own serious neurological condition requiring

¹²² Ibid.

¹²³ ECtHR, *V.I. v Moldova*, no. 38963/18, judgment of 26 March 2024, § 173.

¹²⁴ These stories were collected during interviews conducted by Ms Jolana Miličičová and Mr Maroš Matiaško from FORUM in November 2024 and January 2025.

¹²⁵ The description of facts was prepared by Mr Maroš Matiaško, legal counsel who represents Mr P.V. and René in a domestic proceeding, currently pending before the Brno Regional Court, no. 31 A 51/2024.

treatment, the father had no family support, as René's mother abandoned her parental responsibilities and moved abroad after their divorce.

The father's precarious situation was compounded by his inability to secure suitable social services for René, despite extensive efforts. He repeatedly petitioned various social care facilities and regional authorities, but René was consistently rejected due to a lack of appropriate services or long waiting times. The lack of adequate social care forced the father to shoulder the full burden of caregiving while managing his own health and a full-time job. The absence of proper social care also resulted in René being unnecessarily hospitalised in psychiatric institutions for prolonged periods, which further exacerbated the strain on both René's well-being and the father's ability to provide continuous care. The following tremendously sad statement from an interview on 20 November 2024 of Mr R. demonstrates the enormously challenging situation he had to face due to the absence of adequate social care services:

"I lied to the boy [that they were going to Psychiatric Hospital], I told him he was going to the spa. So I drove him there. He started beating me there as he saw that it was a psychiatric hospital. He started scratching me, punching me, hitting me in the face. He just didn't want to be there, screaming, didn't want to be there. But I just didn't have any other solution."¹²⁶

The last hospitalisation took place in psychiatric Hospitality Kroměříž from 27 July 2024 to 2 September 2024, i.e. 37 days. The very first sentence of the exit report shows a recurring scenario:

"Accompanied by father - **father already exhausted from care**. (emphasis added) René has been short-tempered lately, his moods are changing, he threatened to hurt himself with a cutlery knife at home, he was talking about strange things, they can't handle it at home anymore".

This unsustainable situation caused significant physical, emotional, and financial strain for the father. He suffered psychological distress due to the overwhelming caregiving responsibilities, compounded by instances of physical attacks by René during episodes of aggression. Regional authorities failed to provide any meaningful support, leaving the father and his son in a state of systemic neglect.

In October 2024, René was finally admitted to a social care facility. However, this was achieved solely through the father's relentless efforts, without any meaningful support from the authorities. The absence of institutional assistance prolonged the family's suffering and highlighted the systemic failures in addressing the needs of families caring for individuals with disabilities.

120. The second story is about a family from the Central Bohemian Region, namely of a mother, P.F., who is a primary caregiver of a child with autism, intellectual disability and challenging behaviour who has been unnecessarily detained in a psychiatric hospital in Prague Bohnice since February 2024 due to the unavailability of social care services.¹²⁷

The situation of Mrs P.F.

¹²⁶ Statement from the interview conducted by Jolana Miličičová on 20 November 2024.

¹²⁷ The description was prepared by Mr Maroš Matiaško, legal counsel who represents Mrs P.F. and her son in a domestic proceeding, currently pending before the Prague Regional Court, no. 37 A 66/2024.

Mrs F is the mother of a child diagnosed with autism, moderate intellectual disability, and challenging behaviour requiring high intensive care and support. She suffers from moderate depressive disorder, directly resulting from the stress and demands of caring for her son. This condition further limits her ability to find employment. Since 2010, she has been unemployed, as the care for her son, which has become increasingly challenging with his age and behavioural deterioration, requires her full-time attention. Despite her constant efforts, the family receives no adequate support from the state or access to appropriate social services.

According to the medical report of Mr P., a psychiatrist, dated 17 September 2024, the mother has been diagnosed with moderately severe depressive disorder. The report states:

"The health status of the patient diagnosed with moderate depressive disorder is significantly affected by her socioeconomic status and the care of her severely mentally disabled son, who has so far failed to receive adequate social care corresponding to his level of impairment."

Due to the unavailability of suitable social care services, Mrs F's son was hospitalised in the Psychiatric Hospital Bohnice in February 2024 as a substitute for the required social care. In June 2024, his hospitalisation became involuntary, even though the psychiatric hospital environment was entirely unsuitable for his needs and failed to provide adequate support for his condition. This hospitalisation was a direct consequence of the systemic failure of the regional authorities to ensure the availability of social services for children with ASD and challenging behaviour.

Mrs F has made extensive efforts to secure appropriate residential social services for her son. She contacted numerous service providers, but all reported either full capacity or unsuitability for her son's age group. Despite being fully informed of the situation, the Central Bohemian Region took no effective steps to address the issue of lack of support of care and support to Mrs F' son.

The prolonged hospitalisations and lack of appropriate social care have placed an immense physical and psychological strain on Mrs F. The continuous uncertainty about her son's care, coupled with the inadequate conditions of his psychiatric hospitalisation, has left her exhausted and overwhelmed. The absence of state support and the lack of adequate social services have severely diminished the quality of life for the entire family.

121. The third story depicts the situation of Mr R., the father of Michal, who is a 14-yearold child with autism, intellectual disability, and challenging behaviour.¹²⁸ Mr R. is the primary caregiver. His marriage collapsed due to difficulties associated with care and the absence of support. They live in Prague.

The situation of Mr R.

The father has struggled to find suitable social care services due to severe shortages in capacity for a prolonged period, resulting in Michal's long-term hospitalisation in psychiatric hospitals since October 2023, which has been deemed an inappropriate and non-medical solution to his needs. The father's attempts, as well as the child welfare authorities' attempt to secure appropriate residential social care for his son, were extensive but unsuccessful. From 2023 to 2024, they contacted dozens of care providers across regions in the Czech Republic, facing rejection due to full capacities,

¹²⁸ The description was prepared by Mr Maroš Matiaško, legal counsel who represents Mr R and his son.

Michal's diagnosis, or his young age. The absence of adequate social services has not only kept Michal in a psychiatric hospital longer than medically necessary but also placed an immense psychological and physical burden on the father, exacerbating his exhaustion and concerns for the future of his son's care.

Despite awareness from local and regional authorities, including the child protection authority, about the family's dire situation, no suitable solution has been implemented for two years.

Strikingly, already in February 2024, the psychiatric hospital in Opařany expressed its readiness to discharge Michal. However, due to the unavailability of social care services, he has remained hospitalised. Mr R comments on the passivity of authorities in an interview from 7 November 2024:

"I don't have enemies like at the child welfare authority, for example, or in Prague. **Only it's passive.** I'm not fighting anybody, but **it's more like impotent that the options just aren't there.** There's not that potential to solve it because you have to actually build something of your own or be lucky at the right time in the right place. So **most people are silent and just surviving at home somewhere.**"¹²⁹

Living and working in Prague, the father can visit Michal only once weekly. He is constantly afraid and uncertain, burdened by regret and failure. The lack of support and the absence of social care services resulted in feelings of angriness, severe anguish and suicidal thinking. In an interview on 7 November 2024, Mr R stated:

"Unless we're in ancient Rome where these kids were thrown off a cliff because the society couldn't handle it and the family couldn't handle it at all, and it was the norm, and nobody can be mad at them for it because they were at a certain level of social development. Now, we pretend that that society is more advanced. So if we're further along, then that society should contribute to that and not actually say we're further along, but at the same time leave it up to that family because that family is in the exact same position as in the old Rome. If it's unacceptable that they're throwing themselves off a cliff, then something better must be found. It's a terribly harsh thing to say, I realise that, but what to do? Because I can still jump with him. But the price is high because I'll leave the others behind. And it's really... It makes you feel like you want to jump. And there are cases that end like that."¹³⁰

- 122.Similar feelings of despair and hopelessness due to the unavailability of adequate social care services also portray the story of Mrs Z., a single mother from the Central-Bohemian Region who is a primary caregiver of Sofia, a seven-year-old girl with severe disabilities, including autism, intellectual disability, hyperactivity, and challenging behaviour.¹³¹
 - Mrs Z.

¹²⁹ Statement from the interview conducted by Jolana Miličičová on 7 November 2024.

¹³⁰ Ibid.

¹³¹ The description was prepared by Mr Maroš Matiaško, legal counsel who interviewed Mrs Z. together with Jolana Miličičová, social anthropologist, in the course of research on the situation of caregivers in the Czech Republic.

The care for Sofia presents her mother with immense caregiving demands. Described as being like "a baby," she is non-verbal, wears diapers, and requires full assistance with daily activities such as feeding and dressing. Despite her mother's persistent efforts to find appropriate care, residential respite services – which Mrs Z is trying desperately to find – repeatedly reject Sofie due to her complex needs, citing issues such as hyperactivity, the need for diapers, or a lack of trained staff. The mother is left with no suitable placement options, further deepening her feelings of frustration and hopelessness.

The daily caregiving routine is relentless and physically taxing for Mrs Z., a single mother. Sofie's destructive tendencies and unpredictable behaviour require constant vigilance. Her mother locks and secures household items, manages special restraints in the car, and spends her days preventing accidents or damage. The physical toll is significant; the mother suffers from chronic pain, back issues, and a deteriorating mental state.

As Sofie grows, her mother fears she will become unmanageable, raising concerns about the safety of the household, especially for Sofie's older sister. The fear of future aggression and the absence of long-term care solutions add to her constant anxiety. In an interview from 16 January 2025, Mrs Z. expressed:

"Every day, every night, I think about what will happen to her. Now I go into it knowing that I can't find a daycare, I can't find a school, there are no facilities to place these people with disabilities. Or maybe they will be abused. They don't talk, they don't talk. So nobody will find out that... [Mother bursts into tears] I can't even think about it. That she's going to be abused. I think about it every day. What's gonna happen to her. I think about that every night. I don't want to leave her here alone. And no one's addressing that. That's why the only thing on my mind is that she's going to leave with me. That we'll leave at the same time. That I won't leave her in this world. That's why I don't blame that mom for jumping in front of a train with her kid in Slovakia. Nobody helped her."¹³²

Social isolation compounds the family's struggles. The mother feels judged in public with Sofie, resulting in her avoiding social interactions and relying exclusively on her car for transportation. The lack of respite care exacerbates the problem, as scarce respite services are stretched thin and only offer assistance sporadically – typically only a fraction of the time, e.g. once or twice a year. With no extended family nearby and an absent father who has distanced himself from Sofie since her diagnosis, the mother bears the full weight of caregiving alone. She worries not only about her deteriorating health and well-being but also about the future impact on Sofie's sister, who has already sacrificed her own education to help care for her sibling. Overwhelmed by the challenges, the mother lives in constant despair, fearful of what will happen to Sofie if she is no longer able to care for her.

123.It is apparent from these stories, which – unfortunately, and bearing in mind also above cited documents and statements by Government officials – do not represent isolated incidents but rather are typical in families with higher support needs and consistent with an overall picture of the system that a representative of Olomouc

¹³² Statement from the interview conducted by Jolana Miličičová and Maroš Matiaško on 16 January 2025 with Mrs Z.

region has described as a "chaotic"¹³³, the unavailability and inaccessibility of adequate social care services has a profound impact on caregivers and families. It produces an intense sense of despair and exhaustion. **Caregivers often experience** extreme physical and emotional fatigue, compounded by feelings of isolation as they navigate these challenges often alone. The lack of social care services fosters a deep distrust in the State, as promises made in policy documents and in the law or verbal proclamations of assistance and significance of human rights from authorities remain unfulfilled, leaving families with little faith in public systems.

124. The unavailability and inaccessibility of respite services for families with children with disabilities, especially autism, intellectual disability and challenging behaviour, quite well demonstrates the State Party's indifference to the rights of caregivers. In 2019, the organisation of Czech informal caregivers based in Prague, *Care without barriers* (in Czech *Péče bez překážek*), published a research report concerning respite services in the Czech Republic.¹³⁴ The report focused on the availability and accessibility of respite services for families of children with disabilities, including children with autism, intellectual disabilities and challenging behaviour. The research findings are striking and correspond to the findings concerning the general unavailability and inaccessibility of community-based social care services. According to the report (emphasis added):

"In the Czech Republic, approximately 30,000 families with children with disabilities are striving to care for their children **but lack systemic support from authorities**, healthcare and social service providers, employers, and the community. **Caregivers fear for the future, feel exhausted, and experience a lack of interest from institutions and their surroundings**. The biggest systemic issues are the shortage of social services and limited awareness. The highest demand is for non-residential services, such as personal assistance, day centres, and respite care. The most sought-after forms of support for caring for a child with a disability are accessible personal assistance and respite services (65% of caregivers). We believe that accessible respite services are essential for the sustainable functioning of families with children with disabilities. However, these services are scarce, new ones are not being established, and caregivers are often unaware of existing services. Even the National Strategy for the Development of Social Services for 2016–2025, which commits the Ministry of Labor and Social Affairs to ensure the necessary capacity of community-based social services, has not yet brought the needed improvements."¹³⁵

125. Regarding the statistics, the report provides an overview of the number of available respite service providers for children in 2019, compared to the number of children with disabilities whose families might potentially benefit from this type of social services. It shows severe unavailability and significant regional discrepancies. For example, in the

https://www.pece-bez-prekazek.cz/wp-

¹³³ Statement from the interview conducted by Jolana Miličičová on 7 November 2024 with Mr Z.V., a representative of Olomouc regional authority, on 20 November 2024.

¹³⁴ The report is called *Importance and Availability of Relief Services from the Perspective of Carers of Children with Disabilities.* It is available in Czech at:

content/uploads/2019/06/Vyznam_a_dostupnost_odl_sluzeb_pohledem_pecujicich_o_deti_s_postizenim.pdf

¹³⁵ Importance and Availability of Relief Services from the Perspective of Carers of Children with Disabilities, p. 24.

most developed and most prosperous region, Prague, in 2019, there were only six respite service providers, while there were 2503 children with disabilities.¹³⁶

126.According to the report, "the low number of respite service providers is alarming", and parent carers' current situation concerning respite services' availability is, to say the least, very difficult.¹³⁷ Moreover, the report pointed out that the number of registered respite services does not say much about the accessibility for a particular child with a disability. As the report found, based on data collected directly from caregivers, most of these services were designed for children of specific ages or clients with a selected type of disability. Thus, not all services are accessible to all. Another significant barrier to finding a suitable service was identified as the reluctance of the social care provider to accept a child who is 'challenging' to care for, especially children with more severe behavioural problems.¹³⁸

Regions	Number of Care	Number of Respite	Number of Respite			
	Allowance	Services for	Services Without Age			
	Recipients (0-17	Children (0-17	Restriction			
	years)	years)				
Capital City Prague	2,503	6	1			
Central Bohemian Region	3,592	16	4			
South Bohemian Region	1,803	4	3			
Pilsen Region	1,811	5	1			
Karlovy Vary Region	881	0	0			
Ústí nad Labem Region	3,211	4	1			
Liberec Region	1,478	8	0			
Hradec Králové Region	1,731	2	0			
Pardubice Region	1,853	4	0			
Vysočina Region	1,324	3	4			
South Moravian Region	3,483	2	3			
Olomouc Region	1,74	3	1			
Moravian-Silesian Region	3000	9	2			
Zlín Region	1,634	4	2			
TOTAL	30,044	70	22			

Table no. 4: Overview of respite care services providers in 2019

127. Data from the Ministry of Social Affairs can supplement this overview from 2019. The Ministry of Social Affairs collects data on the number of respite service users (non-residential).¹³⁹ As the graph below shows, in 2023, there were only 947 users under

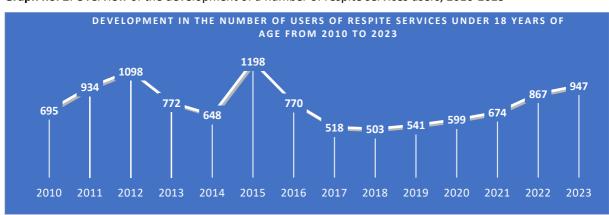
¹³⁶ Between 2021 and 2023, this number rose by three thanks to the lobbying of caregivers See, in Czech: <u>https://www.pece-bez-prekazek.cz/advokacni-prace/</u>

 ¹³⁷ Importance and Availability of Relief Services from the Perspective of Carers of Children with Disabilities, p. 24.
 ¹³⁸ Ibid.

¹³⁹ It is necessary to note that the government has only collected information about ambulatory and outreach respite services. The data on residential respite services should be available in 2025. Yet, the data shows a pattern, namely, the absence of growth of respite services and a very high number of declines.

the age of 18 in the whole Czech Republic. The peak number of users was recorded in 2015 (1198 users), rapidly decreasing by more than 50% in the following three years (only 503 users in 2018) and slightly increasing since then. **The growth of this crucial social care service for families with children with disabilities**, and especially with children with high-level needs, such as children with autism, intellectual disability and challenging behaviours, has been affected by substantial retrogression and a very slow pace of development.

128. At the same time, the Ministry of Social Affairs records that in 2023, as many as 4051 potential users were refused respite services.¹⁴⁰ This number covers minors and adults. While it is impossible to precisely state how many families with children with disabilities were refused because the Ministry of Social Affairs does not record this number, we may presume that approximately 1/3 may concern families with children. In other words, quite probably more families with children with disabilities were refused with respite services that benefited from this type of service.



Graph no. 2: Overview of the development of a number of respite services users, 2010-2023

Source: Ministry of Social Affairs, Statistical Yearbooks, 2010-2023

- 129. Moreover, as shown in Table no. 5, in 2023, almost no families of children with disabilities have used respite services in several regions. Strikingly, in Ústí nad Labem, there were only six users; in the Vysočina region, only four users; in the Hradec Králové region, 12 and 14 users in the Zlín region. At the same time, there were 337 users in Prague. These numbers point to significant regional disparities and extreme inaccessibility of respite services outside Prague. Moreover, the table also points to the non-development of respite services and even a decline in some regions across the Czech Republic. For example, in the Karlovy Vary region, in 2010, 84 families used respite services; in 2023, only 62 families. Users in the Central Bohemian Region fell from 160 in 2010 to 142 in 2023.
- 130.In **2015**, the National Strategy on the Development of Social Care, adopted by the Ministry of Social Affairs, **described the situation of caregivers as precarious**, including regarding the lack of respite services. According to the National Strategy, "**[c]aregivers face many shortcomings in current social services and long-term care policy**," including issues related to the "**underdeveloped network of support services (e.g.**,

¹⁴⁰ Typically, this is because of the unavailability of places or different target groups.

crisis respite services)."¹⁴¹ The measure identified – in 2015 (sic!) – was to "develop new measures" to support caregivers, including "respite services."¹⁴²

Region	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019	2020	2021	2022	2023
Capital City Prague	39	214	220	232	104	95	81	144	133	150	158	203	281	337
Central Bohemian region	160	257	324	211	109	545	421	128	120	139	167	156	154	142
South Bohemian region	18	0	0	11	10	2	20	35	41	42	59	59	77	74
Pilsen region	21	27	267	15	3	258	40	16	16	19	27	26	38	52
Karlovy Vary region	84	111	87	122	125	2	4	1	0	3	6	35	59	62
Ústí nad Labem region	5	2	2	15	71	76	19	10	8	6	7	2	3	6
Liberec region	17	16	14	12	8	8	10	12	23	11	23	35	35	49
Hradec Králové region	193	7	9	7	29	14	12	15	9	12	17	14	17	12
Pardubice region	1	9	11	11	7	9	12	10	13	13	8	11	17	16
Vysočina region	19	19	29	22	35	28	37	9	1	5	5	4	3	4
South Moravain region	38	26	45	9	4	13	0	16	22	29	33	27	28	41
Olomouc region	15	18	19	24	27	24	26	20	28	28	23	32	45	49
Zlín region	23	25	25	30	29	22	27	24	13	9	7	14	14	14
Moravian-Silesian region	62	203	46	51	87	102	61	78	76	75	59	56	96	89
in total	695	934	1098	772	648	1198	770	518	503	541	599	674	867	947

Table no. 5: Number of children using respite services (non-residential), 2010-2023

- 131. The 2015 National Strategy contains a list of specific objectives. One of the objectives is defined as "increase support for caregivers through social and health care services", allocating responsibility of the Ministry of Social Affairs to "prepare a proposal on how to provide e.g. respite services for informal caregivers". A specific measure identified within this objective is described as "[s]ystematically ensure that the capacity of respite and care services is allocated for cases when the family cannot provide sudden care".¹⁴³
- 132.Since 2015, the State Party has been fully aware that respite services are scarce and that ensuring their availability and accessibility is urgently necessary. However, as the data shows, **the State Party has not ensured adequate capacity growth in the past ten years**, particularly concerning families with children with disabilities. In this regard, it has to be noted that in 2021, the UN Committee on the Rights of the Child (hereinafter "CRC Committee") expressed several concerns regarding the State Party's failure to adhere to caregivers' rights (CRC/C/CZE/CO/5-6 22 October 2021). The CRC Committee requested the Czech Republic to:

"Develop and finance social and community-based services to detect and support families in situations of particular vulnerability, including due to socioeconomic situations, those raising children with disabilities and single-parent families, and provide timely and targeted services, including field, outpatient, respite and social

¹⁴¹ 2016-2025 National Strategy of the Development of Social Care Services, p. 28. Document is available in Czech at: <u>https://www.mpsv.cz/documents/20142/577769/NSRSS.pdf</u>

¹⁴² *Ibid*, p. 29.

¹⁴³ *Ibid*, p. 75.

activation **services**, to prevent child abandonment and family separation and facilitate returns of children; (para. 29(b)).

... Strengthen support for the parents of children with disabilities, including those with very serious, combined or rare disabilities, to meet the demand in urban, rural and remote areas, reduce regional disparities and ensure the right of those children to grow up in their family environment, including by increasing the availability of early care, home nursing and relief services, creating a network of community and outpatient health-care services, training and ensuring an adequate number of paediatricians, child psychiatrists and psychologists and ergotherapists, providing timely and adequate socioeconomic support to all children with disabilities, regardless of their age and type of disability, and improving outreach to parents about the services available (para 35(d)).

133. In conclusion, the State Party is aware of the precarious situation faced by caregivers, including the unavailability and inaccessibility of respite services for at least a decade. However, as the stories and data presented above indicate, the Czech Republic has failed to take appropriate steps to ensure the rights of caregivers, particularly family caregivers of children with high-level needs, such as those with autism, intellectual disabilities, and challenging behaviour. This includes ensuring the availability and accessibility of an adequate number of appropriate care solutions and social services tailored to the needs of persons with high-level needs and developing a network of accessible respite services. Consequently, the situation in the Czech Republic violates Article 16 of the 1961 Charter.

IV. CONCLUSION

- 134. In ratifying the European Social Charter, the Czech Republic indicated its intention to fully ensure the rights enshrined in Articles 11§1, 11§3, 14§1, 14§2, and 16 while upholding the principle of equality, thus guaranteeing that all individuals with disabilities have access to available, accessible, and quality community social care services. This includes adults and children with high-level needs, such as those with autism, intellectual disabilities, and challenging behaviour. It also aimed to facilitate their involvement in developing the network of social care services and to ensure effective protection against inadequate care solutions, such as unnecessary psychiatric hospitalisation. Furthermore, the Czech Republic sought to protect the rights of informal caregivers, including single parents and families of children with high-level needs, such as those with autism, intellectual disabilities, and challenging behaviour. However, this complaint illustrates that the State Party has failed to comply with Articles 11§1, 11§3, 14§1, 14§2, and 16 of the 1961 Charter, as well as the principle of equality recognised in the Preamble to the 1961 Charter.
- 135. For these reasons, Autism Europe, jointly with the Forum for Human Rights, asked the European Committee of Social Rights to find, especially:
 - violation of Article 14§1 and Article 11§3 of the 1961 Charter for a failure to ensure independent living of people with disabilities;
 - violation of Article 14§2 of the 1961 Charter for a failure to ensure the participatory rights of people with disabilities and their caregivers;
 - violation of Article 11§1 of the 1961 Charter and Article 11§3 of the 1961 Charter for a failure to ensure the rights of people with disabilities and with high-level needs, especially children with autism, intellectual disability and challenging behaviour;
 - violation of Article 16 of the 1961 Charter for forcing caring families, especially families of people with autism, intellectual disabilities and challenging behaviour, into precarious situations;
 - the violation of the invoked provisions of the 1961 Charter should also be considered in light of the non-discrimination clause established in the Preamble to the 1961 Charter, particularly regarding Articles 11§1, 11§3, and 16 of the 1961 Charter.

In Brussels and Prague

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19 March 2025

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