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Third-party observations

A consortium of Czech organisations of persons with disabilities and non-governmental organisations in the collective complaint

Autism-Europe v. the Czech Republic, No. 245/2025

Introduction

1. This third-party intervention is submitted in relation to the collective complaint *Autism Europe v. the Czech Republic* (complaint no. 245/2025) by representatives of eleven Czech Organisations of Persons with Disabilities and Non-Governmental Organisations (NGOs) (*hereinafter* "the Consortium").
2. The Consortium brings together different members, who are persons with disabilities or informal caregivers and work directly with persons with disabilities, autistic persons, persons with intellectual disabilities, persons with high support needs, informal caregivers, families and community-based service providers. The purpose of these observations is not to duplicate the complaint lodged by Autism-Europe and Forum for Human Rights. The Consortium submits additional evidence to assist the Committee in assessing the practical operation of the Czech

social care system. In particular, the submission explains how the existing social care system fails in practice; how the system transfers responsibility to families and informal caregivers; and how this produces pressure towards institutionalisation or psychiatric hospitalisation when community-based support breaks down.

3. The Consortium relies on four recent principal sources:

    i. Research Report *Životní podmínky pro osoby s vysokou potřebou péče* [Living conditions of people with high care needs] by PAQ Research, published in March 2026,[1]

    ii. Research Report *Strategie přežití* [Strategies of survival] by the NGO Žít po svém, research conducted from September 2025 to January 2026,[2]

    iii. Research analysis Klusáček, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním (a seniory) v Česku* [Analysis of basic data on the capacity and funding of social services for people with disabilities (and older people) in the Czech Republic]. Prague: JDI, z.s. and MoLSA, April 2026,[3]

    iv. The submission further incorporates evidence from the *Open Letter,* a petition supporting the collective complaint filed by *Autism-Europe*, signed by up to 1,201 signatories from across the Czech Republic (open for signatures from November 2025 to January 2026).

4. The evidence is directly relevant to the Committee's assessment of whether the Czech Republic secures the rights guaranteed by the European Social Charter in a practical and effective manner. The consortium asserts that the core issue is not only whether social care services are formally recognised in domestic law or whether the Government has adopted policies. The decisive question is whether persons with disabilities and their families can actually access the intensity level, type and continuity of support required to live in the community and

[1] DUARTE, Jana; RÖSCHOVÁ, Michaela and ŠPALEK, Jan. *Životní podmínky osob s vysokou potřebou péče*. Research Report. PAQ Research, March 2026. Available: https://www.paqresearch.cz/content/files/2026/03/PAQ_Asistence_vyzkumna_zprava2026.pdf

[2] AUGUSTINOVÁ, Jana; DVOŘÁKOVÁ, Lenka and PRAGER, Michal. *Strategie přežití.* Research Report. Žít po svém. Available at: https://zitposvem.com/wp-content/uploads/2026/03/Zit-po-svem_Strategie-preziti_Vyzkum_02.pdf

[3] The analysis is available in Czech at: https://jdicz.eu/analyza-zakladnich-dat/

independently, avoid unnecessary institutionalisation, maintain family life, and participate in ordinary social life on an equal basis with others. The existing research reports, as well as real-life stories collected by the Consortium members, show that the social care system is primarily focused on institutional care, while community care has not been adequately supported. The unavailability and inaccessibility of community care is compensated for by informal care and provided, without adequate state support and often at the cost of the person's sacrifice, by informal caregivers (family members and loved ones). This affects not only people with disabilities but entire families, forcing them into precarious conditions, negatively affecting their health, work and relationships.

1. Community support is formally recognised but not effectively accessible

5. Legal recognition of community-based social care remains ineffective in practice. A typical example is the failure to ensure that personal assistance services are available and accessible. The *Strategie přežití* [Strategies of survival] report shows that, in practice, personal assistance remains unavailable and inaccessible. **The most serious gaps concern night-time support, weekend coverage, limited service capacity, sudden deterioration in health, and crisis situations.** These are precisely the situations in which persons with high support needs require reliable, immediate assistance.

6. People with disabilities are routinely forced to adapt to these limitations through a range of **coping strategies** such as restricting daily fluid and food intake, remaining in a static sleeping position, reducing evening activities, or suppressing the need to call for help. These practices are not free choices. They pose risks to their health and, at the same time, highlight the **absence of systemic mechanisms** to ensure substitute support in the event of informal care failure.

7. The case of **Kačka**[4] illustrates this gap. She needs approximately 14 hours of assistance per day, but usually has access to only 8 to 11 hours. She is signed up for 55 hours of personal assistance per month, which she regularly exceeds. The gap between need and availability is bridged by a combination of rescheduling hours, using emergency services, help from family, and, above all, consciously limiting her own needs. Essential daily activities such as eating, drinking, and

[4] *Strategie přežití,* pp. 72-74.

using the toilet are adjusted to the availability of assistance rather than natural bodily needs: "*The bathroom, drinks, food—those are the things I cut back on the most*."

8. Her family functions as a compensatory mechanism for the system. Her mother regularly helps Kačka "make ends meet" with her schedule and finances. Due to a lack of assistance, Kačka spends more time with her parents than would be appropriate for her age and stage of life. The family thus does not fulfil a supplementary role but replaces the missing systemic support.
9. In practice, family members and loved ones do not represent a supplementary component, but rather a structurally vital pillar of care and support. The transfer of responsibility to families, without corresponding financial and systemic support, leads to their exhaustion, the distortion of relationships, and a high degree of vulnerability for persons with disabilities whose life stability depends on a specific close individual.
10. A particularly serious finding is that, in extreme cases, **respondents consider radical solutions, including thoughts of ending their lives, if the alternative to weak and untenable home support is long-term institutionalisation**. These considerations cannot be interpreted as manifestations of individual psychological crises, but rather as a consequence of systemic failure to provide sufficient support capacity to meet individual support needs and to ensure a dignified life in the community.
11. These circumstances give rise to a situation in which the safety and dignity of life depend on a confluence of uncertain factors, particularly the combination of formal and informal care and the absence of systemic backup mechanisms. The system thus formally states the option of community living for all, but without a genuine guarantee of stability and security, it allows only low-intensity support that cannot meet medium or high support needs. This creates a **push to institutionalisation** as the lack of accessible personal assistance in practice increases the risk of involuntary institutionalisation.
12. The findings clearly demonstrate that the availability of personal assistance often remains a mere declaration, with nighttime and emergency support systematically absent, leading to protracted self-restrictive strategies and, in extreme cases, to the perception of the future in an institution as an existential risk. These conclusions indicate that the current support system is not designed as a guaranteed

instrument for the realisation of rights, but rather as a capacity-limited service whose availability is insufficient to ensure a dignified and safe life for persons with disabilities in accordance with their fundamental rights.

2. The system shifts responsibility to families and informal caregivers

13. The *PAQ Research* report confirms significant systemic overreliance on informal care, which remains a fundamental, often the only source of support for persons with high support needs. More than half of informal caregivers report being permanently available, and 42% provide care for at least 80 hours per week. This level of unpaid or under-supported care cannot be characterised as ordinary family solidarity; it is systemic substitution.

14. Informal caregivers (most often women) provide long-term, intensive, and frequently irreplaceable care. Caregivers provide care and support on a daily basis, with more than half (56%) always available. More than two-fifths of respondents (42%) provide care for at least 80 hours a week, averaging more than 11 hours a day. They are also available at night or during a lapse of formal care.

15. The consequences for informal caregivers are severe. Many reduce or leave employment, while a majority experience significant physical and psychological strain (74%), including high levels of exhaustion and negative health effects (56%) like chronic stress, social isolation, and symptoms of depression or anxiety at rates far above the general population. The absence of an accessible replacement for informal care further worsens this situation, forcing caregivers to continue providing care and support even when ill or exhausted. At the same time, financial support mechanisms, including care allowances, remain insufficient to either compensate caregiving adequately or enable a sustainable balance between care and employment.

16. The *Open Letter* reinforces this conclusion. Its 1,201 signatories came from across the Czech Republic. The largest numbers were from Prague, the Central Bohemian Region, the South Moravian Region and the Moravian-Silesian Region, but all regions were represented. The largest group of signatories was parents of persons with disabilities (824), followed by other informal caregivers (116), persons with disabilities themselves (70), social service providers (63), and representatives of parent organisations and groups (48). **This distribution matters: the evidence is**

not an isolated local complaint, but a nationwide account of systemic over-reliance on families.

17. The situation described in the *Open Letter* by various petitioners shows the same pattern. A mother from Prague has been caring for her daughter with high-level needs for almost 17 years. She has described the care as long and exhausting, with no meaningful support from the state. Due to the lack of support, she cannot work, and her family lives in social isolation with dire consequences for her mental and physical well-being and relationships. The school reduced its hours when her daughter could have been there, and respite services refused them. Personal assistance is unavailable, and the family has no means to privately fund any support.

18. A mother of two sons with autism and intellectual disabilities from the Olomouc Region stated - when signing the *Open Letter* - that for more than 20 years she has been providing round-the-clock care without the ability to work and without any real support from the system. She has described long waits for welfare services, during which applications are repeatedly rejected or remain unresolved for years, while also pointing out the significant bureaucratic burden and frequent lack of interest on the part of institutions. She has noted that care involves daily management of aggressive behaviour, destruction of property, and physical assaults, which leads to extreme mental and physical exhaustion. She has stated that she has had no opportunity for even basic rest or independent functioning and has lived in constant fear for the future.

19. Another mother from the Olomouc Region, who has cared for her son in the highest degree of dependency for more than thirty years, describes being fully dependent on a pension and care allowance, unable to work, and without ordinary employment protections. She fears that if she dies, her son will be placed in institutional care; if her son dies, she risks falling into material deprivation despite a lifetime of caregiving.

20. The limited availability of formal support is also reflected in the capacity of respite care services, which should serve as one of the key tools for preventing burnout among families and informal caregivers. According to a very recent analysis by Klusáček, the capacity of respite care services provided in the field amounts to approximately 506 full-time job equivalents in direct care. In 2024, these services

supported 4,323 clients for a total of 381,505 hours, averaging only **1.7 hours of support per client per week**.[5] The ambulatory form of respite care services had a capacity of approximately 87.5 full-time job equivalents in direct care, supported 929 clients for a total of 104,209 hours, and provided an average of 2.2 hours of support per client per week.[6]

21. These figures confirm that respite care services, at their current scale, cannot fulfil the role of a stable, systemic support system for families caring for individuals with high support needs. If the average intensity of support in both outreach and ambulatory respite care services is only a few hours per week, it cannot be considered a sufficient mechanism to prevent caregiver burnout, crisis situations, or subsequent institutionalisation. The insufficient capacity of respite care services thus further confirms that, in practice, **the system relies on informal care as the primary source of support without providing families with adequate and sustainable compensation or backup.**

3. Insufficient support distorts personal relationships and creates extreme precarity for informal caregivers

22. The shortage of formal support does not merely create inconvenience or administrative difficulty. It changes the substance of personal relationships. When partners, parents and relatives become the only reliable source of support, relationships of family life, partnership and friendship are transformed into compulsory care arrangements.

23. **Adam's**[7] story illustrates this point. He is 30 years old and lives with his girlfriend in a multigenerational family home. He has a severe physical disability and is a long-term user of personal assistance and informal care. Adam receives only 24-30 hours of personal assistance per week, and the majority of his care is provided by his partner, mother, and wider community. His daily life is tightly structured around the availability of assistance, leaving little room for flexibility and making

[5] KLUSÁČEK, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním v Česku*, p. 23.
[6] KLUSÁČEK, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním v Česku*, s. 40.
[7] *Strategie přežití*, pp. 52-53.

the entire household vulnerable to any disruption. In practice, the system relies on informal care as a primary mechanism, rather than as a complementary one.

24. This transfer of responsibility has **profound consequences for personal relationships and individual well-being**. Adam describes how the lack of sufficient assistance gradually transforms his partnership into a caregiving relationship, eroding mutual roles, autonomy, and intimacy: "*The boundaries of your identity are blurring. You're no longer a partner or a friend—you're being looked after.*"

25. To reduce the burden on his partner, he adopts long-term strategies of suppressing his own needs and emotions, which negatively affects his identity and self-worth: "*The more you put yourself and your emotions in the background, the better you'll handle it. But it comes at a huge cost. Society fosters the burden syndrome in us. We choose strategies where we put ourselves in the background and are grateful for the bare minimum.*"

26. **The absence of adequate systemic support thus not only places disproportionate demands on families but also reshapes fundamental aspects of life**, including relationships, mental health, and the ability to live with dignity, free of precarity.

27. This pattern is confirmed by the open-letter evidence and concerns also informal caregivers. A single mother in the South Moravian Region, caring for a son with autism, mild intellectual disability and ADHD, reports that she has no family support and had to leave employment because of repeated school crises. She describes being alone, exhausted, and without access to or affordable services. Her fear is not only present hardship, but the future risk of collapse if something happens to her.

28. A Prague single mother caring for a son with Down syndrome and autistic traits describes a similar dependency on informal support. Without help from her parents, she could not work or pay rent because the care allowance was insufficient for basic living costs. Repeated failures to secure assistance and appropriate education left her son at home for a year without adequate support. The mother worked under constant fear of crisis at home, including property damage, harm to the family dog, or fire. Even eventual placement in supported housing did not remove concerns about staff shortages and the quality of support.

29. A mother from the Moravian-Silesian Region, who cared for her son with an intellectual disability and autism accompanied by aggressive behaviour for 37 years, has described the long-term failure of the system, having spent more than 13 years unsuccessfully trying to secure a suitable social care provider for her son. Due to the absence of social care services, her son was repeatedly hospitalised in psychiatric wards. The care led her to complete mental exhaustion and health problems, and she reached a state of despair, even contemplating ending her life. After placing her son in a facility 60 km away, she has described her own financial insecurity, as after decades of care, she faces very low benefits and the threat of poverty: *"I ended up at the unemployment office, where they calculated my unemployment benefits at an average of 5,000* [approximately 200 EUR] *a month. And again that feeling of hopelessness. For having cared for my disabled son for 37 years—without being entitled to vacation, sick leave, or any private life, cut off from everything going on—I received a pittance that isn't even enough to pay for my apartment. I've always been thrifty; thanks to my savings, I'm still alive, but once they run out, I don't know what will happen."*

30. A mother of two children with autism and intellectual disabilities from the South Moravian Region has pointed out the lack of respite care services, the social isolation of families, and their state of near physical and mental exhaustion. She has explained that she cannot work because of her caregiving responsibilities, has been searching for a caregiver for a long time without success, and that financial support does not even cover basic needs, let alone therapy or assistive devices. She also mentioned the impact on her partner, who faces problems at work due to caring for the children, and speaks openly about extreme exhaustion and thoughts of suicide: *"Personally, I've been so exhausted over the last few weeks that I'd rather just end it all."*

4. Lack of adequate care and support creates pressure towards institutionalisation, including psychiatric hospitalisations

31. The Consortium's evidence shows that institutionalisation remains the default risk when family care collapses. This pressure is not always explicit. It is created indirectly by insufficient community services, a lack of crisis support, limited personal assistance, inaccessible respite care, and financing structures that continue to favour residential services.

32. **Viktorie's**[8] story demonstrates the gravity of this risk. She is a 33-year-old woman with spinal muscular atrophy and epilepsy, which poses a real and unpredictable threat to her life. Seizures can occur suddenly, without warning, and at such times she cannot be left alone (she stops breathing during seizures). Nevertheless, the personal assistance system does not adequately reflect this reality; despite her need for round-the-clock care, she was denied Level IV (highest level of care allowance).

33. Viktorie lives with her parents and her partner. Care is thus divided between the family and the partner who function as an informal backup for the system, not as voluntary caregivers with a choice. Her close relationships thus function as an involuntary safety net rather than a complementary form of care, reflecting the absence of a reliable, comprehensive support system: "*That stress about the future is always there, even when I'm not actively thinking about it.*"

34. Within such a context, **Viktorie talks about assisted suicide if her non-formal support system collapses**. This is not a symptom of acute psychological distress, but a rational response to systemic insecurity. It represents a perceived last-resort safeguard against potential care collapse, offering a sense of control where the system provides none. Her situation is shaped by long-term uncertainty: ageing parents, limited capacity of her partner, and the lack of alternatives that would preserve dignity and autonomy. Institutional care is viewed not as support, but as a loss of meaningful life, underscoring the extent to which the system fails to provide a viable and secure framework for independent living: "*I'd have to adapt my whole life to a collective facility. That's unimaginable to me*."

5. Financing and staffing data reveal a structural preference for residential services

35. The recent analysis by Jan Klusáček, based on data from the Ministry of Labour and Social Affairs, confirms that the imbalance between residential and community-based services is structural. For example, personal assistance currently operates with approximately 2,500 full-time equivalent positions serving around 11,060 clients, which corresponds to an average of **only 4.7 hours of assistance per client per week**.[9] This level of provision is manifestly insufficient

[8] *Strategie přežití,* pp. 66-68.

[9] KLUSÁČEK, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním v Česku*, p. 20.

for the needs of persons with high support needs and demonstrates that personal assistance is not provided at a level capable of ensuring the effective realisation of the right to independent living.

36. **The distribution of staff reflects the same pattern**. Approximately 12,000 full-time equivalent workers are available in outreach services, including personal assistance, while the broader residential system for persons with disabilities and older persons includes approximately 46,500 workers.[10] This demonstrates a continued orientation towards institutional care.

37. The **funding structure reinforces the point**. Allocations from the state budget distributed through regional authorities amount to approximately CZK 14.44 billion for residential services, compared with CZK 4.72 billion for outreach services and CZK 1.88 billion for ambulatory services. Comparable disparities appear at the regional and municipal levels. The result is that community support remains underdeveloped, while residential services continue to absorb the dominant share of resources.

38. The system's structural focus on residential care is evident not only in the allocation of financial and human resources but also **in the very nature of existing residential facilities**. The analysis shows that there are a total of 15,113 places in residential social services for people with disabilities. Of these, 9,683 places are located in facilities with more than 18 places, of which approximately 3,400 places are in facilities with 100 or more places.[11] These data indicate that **a significant portion of residential capacity remains concentrated in larger facilities**. This supports the conclusion that the Czech social services system continues to adhere to an institutional logic that is difficult to reconcile with the requirements for genuine community living, individual support, and the prevention of segregation of people with disabilities, including people with autism and intellectual disabilities.

[10] KLUSÁČEK, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním v Česku,* p. 67.
[11] KLUSÁČEK, J. *Analýza základních dat o kapacitách a financování sociálních služeb pro osoby se zdravotním znevýhodněním v Česku,* p. 51.

Conclusion

39. The accounts summarised above are not isolated tragedies. The evidence discloses systemic, not exceptional, failures; it displays repeating features across regions and family situations within the Czech Republic.

40. The evidence demonstrates that the Czech system continues to rely on institutions, families, and informal caregivers as the primary care and support network. The effect is particularly dire for autistic persons and their families, as well as persons with intellectual disabilities, persons with high support needs and their families. The Consortium submits that the evidence reveals systemic deficiencies in the Czech Republic's compliance with the European Social Charter.

Yours sincerely,

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on behalf of the DPOs and NGOs Consortium

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