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POSITION PAPER

**For a European Directive on the Right to
Independent Living for Persons with Disabilities**

**Addressed to the European Commissioner for Equality,
the Members of the European Parliament (EMPL and LIBE
Committees) and the European Commission (DG EMPL)**

2025–2026

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About KEEP DRIVEN

The project “KEEP Driven: Promoting the Knowledge, Leadership, and Participation of Young People with Disabilities” is being implemented in Italy, France, Latvia, and Belgium thanks to co-funding from the European Union under the Erasmus+ program. Its aim is to strengthen the knowledge and leadership of young people with disabilities and promote their full and effective participation in democratic life. Rooted in the values of democratic participation, self-advocacy and peer learning, the project supports young people with disabilities in exercising their right to participate in the political and civic life of their communities and of the European Union. The present position paper is one of the project’s central outputs: a document prepared by and for young people with disabilities, addressed to European and national institutions, demanding systemic change.

We, the young participants of KEEP DRIVEN, come from three different countries, have different disabilities, different life stories and different languages, but we share a conviction: the right to live independently is not a privilege, a reward or a favour. It is our fundamental human right — and it must be enforceable, everywhere in Europe, for everyone.

Our voice

Who are we and what independent living means to us

“My name is Arthur Tauran. I’m 24 years old, I’ve had cerebral palsy since birth, and I live in Toulouse, France. I have a master’s degree in computer science and launched my business, Dreambyrage, at the end of my studies in October 2024 to create electronic music and audiovisual content aimed at changing perceptions of disability.

I have been a member of APF France handicap for 6 years and have been volunteering locally for 2 years (accessibility group). For the past year and a half, I have been attending the National (inter-organizational Master Class in Governance and Engagement) and joined the National Youth Initiative Group eight months ago. It was in this capacity that I joined the Keep Driven project. It was an opportunity for me to do an ERASMUS exchange, something I’d wanted to do for a long time because I saw the (able-bodied) members of my family doing it. And, secondly, I found the project deeply meaningful. For me, independence means being able to do something without worrying about the challenges posed by my disability and without having to plan ahead.”

“I’m Alessia and I took part in this project because I experience how hard it can be living with a disability. However, I believe it shouldn’t be a limit and that’s why I began this path through independent living. To me, independent living means life: it’s when you can count on your own resources, that can be in your body or in someone else’s body. Independence is the right to choose what you want and independent living is the possibility to choose in every single moment of your life, what you want to do.”

“I took part in the KEEP DRIVEN Erasmus+ project because I was interested in meeting and talking with other people with disabilities who — by age and by everyday life — might want to confront some of the common difficulties that exist at a structural level in ordinary life.

Growing up, I have realized more and more that many needs are not only mine, and I firmly believe that change can only be brought about if it is shared. Taking part in the project confirmed this idea, and confirmed how the possibility of choice can be claimed as a human condition — not as a constant struggle or a distant utopia.

For me, independent living perhaps means this: being able to think about something I would like to do, without first having to weigh the obstacles that would stop me from doing it. In everyday life it means getting up on a Sunday without rushing, having a coffee before taking a shower, not having to think about who and how I can ask to be helped with something, going to the bathroom when I need to and not by schedule, being able to go out for dinner or on holiday with whoever I want — helped by someone I trust and on whom I can choose to depend — wanting and expressing an emotional and sexual life, and the thousand other interactions that let a person live everyday reality freely.” (Carlo)

Our voice

Who are we and what independent living means to us

“My name is Sofia, I’m 23 years old and I’m a university student. I took part in the training sessions for this project through Ledha. I chose to take part so that I could connect with other people with different disabilities and because I wanted to share my experiences with others.

For me, living independently means being able to carry out tasks that I know I am capable of doing on my own, in an environment that is suitably adapted to my needs. It also means that access to everyday activities (such as using public transport) must be made easier and, at the very least, guaranteed by those who can provide support, even if it’s minimal.” (Sofia)

Executive Summary

This position paper, prepared by young people with disabilities participating in the KEEP DRIVEN Erasmus+ project, makes a formal call on the European Parliament and the European Commission to adopt a binding European Directive on the Right to Independent Living for Persons with Disabilities.

Key Points

- The Right to Independent Living, enshrined in Article 19 of the UN Convention on the Rights of Persons with Disabilities (CRPD) and in the EU Charter of Fundamental Rights (Article 26), remains systematically violated across Europe. More than 1 million persons with disabilities live in institutional settings across the EU, and institutionalisation has increased by 29% over the past decade in those Member States where data is available (Eurofound, 2024).
- No binding EU legal framework currently guarantees minimum standards for personal assistance, deinstitutionalisation or community-based living. The EU Disability Rights Strategy 2021-2030 and the European Commission's Guidance on Independent Living (November 2024) represent important political commitments but remain non-binding instruments insufficient to close the implementation gap.
- The three countries represented in this project — Italy, France and Latvia — illustrate the depth of this inequality: institutionalisation has increased by 101% in France and 36% in Italy over the past decade, while Latvia has achieved a 12% reduction through EU-funded deinstitutionalisation. This contrast demonstrates that reform is possible — but requires binding legal obligations, not voluntary guidelines.
- We call on the European Parliament to exercise its right of initiative under Article 225 TFEU to request the European Commission to present a formal proposal for a Directive on Independent Living, setting mandatory minimum standards for personal assistance, deinstitutionalisation time-lines, and the use of EU structural funds.
- Independent living applies to ALL persons with disabilities, regardless of the nature or level of their support needs, including those with intellectual, psychosocial and complex disabilities. The right cannot be restricted on the grounds of impairment or the degree of support required.

1. Introduction

Independent living is not merely a policy concept. It is the foundation upon which all other rights rest. As the CRPD Committee has made clear in its General Comment No. 5 (2017) on Article 19, independent living is ‘one of the widest ranging and most intersectional articles’ of the Convention: without it, persons with disabilities cannot access education, cannot exercise the right to work, cannot participate in political life, cannot form families of their own, cannot enjoy the freedoms that non-disabled citizens take for granted.

As Adolf Ratzka, a pioneer of the independent living movement, wrote: ‘Independent Living means that we demand the same choices and control in our every-day lives that our without disabilities brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours and work in jobs that are in line with our education and interests, and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves — just as everybody else.’

We are a group of young people with disabilities. We know from our own lives what it means when this right is denied. We know the weight of being told where to live, who will care for us, what we are allowed to do and what we are not. We know the difference it makes — for dignity, for freedom, for the future — when genuine choice and real support are available. This position paper is our collective demand for change.

Our story

When the right to choose is denied or limited. How it made us feel and what could have been different with the right support

“As part of my graduate studies in computer science, I completed several long-term internships at a computer science research lab in the department focused on disability, specifically the development of human-machine interfaces.

I realized that my slow motor skills, due to my disability, put me at a disadvantage—not only in terms of my internship choices, since the private companies I applied to didn’t respond, but also in my work at the lab, even though my supervisors were understanding.

I loved the project I was working on and wanted to make progress, but I could see that, compared to my classmates, I was producing half as much each day, and that was frustrating.

Today, when I see the progress of Artificial Intelligence, I tell myself that if I’d had that tool, I could have been much more efficient.” (Arthur)

“I didn’t have the opportunity to choose between living in a dormitory and an apartment. I felt obliged to choose the dormitory because it has accessible rooms, whereas for an accessible apartment I wouldn’t even have known where to look. I think that with the right support on searching I would have found one.” (Alessia)

Holidays, social life, events I did not attend or cancelled at the last minute because there was no one to help me, and because I did not want my friends to become responsible for me, or to be a constant limit on the others.

Taking part less and less in academic and university life, because it was too tiring to manage without any physical help. Having to eat depending on whether someone was there to help me, or skipping meals. Going to the bathroom without the urge, or holding it for half a day. Having to be washed, dressed and looked after by my parents, when neither I wanted it nor they were able to do it. All the frustration, the anger, the loss of hope, the pain, the loss of meaning, the anxiety, the claustrophobia, the disgust towards myself, the loneliness and the abandonment of having to manage something that, growing up, sometimes feels too big to manage alone, with no idea how to do it. For me, support is a resource so as not to have to live through much of this — or not to have to live it every single day, for the whole of my life. (Carlo)

Our story

When the right to choose is denied or limited. How it made us feel and what could have been different with the right support

I attend a university that is known both in Italy and abroad, and which is also attended by many people with different disabilities. I was very surprised and frustrated that, despite the existence of an inclusion office, the activities it carries out are very limited: in terms of teaching organisation and how students take part in the exams, as well as guidance within the university and support in the classroom. Furthermore, this office does not provide practical assistance during lectures (for example, taking notes or using the various spaces within the university), an aspect that would be very important for a person with a disability. Only during the exams there is a specific support (for example, a person who reads or writes for the student), but not during the entire course.

I was surprised because the university has plenty of space and staff; therefore, I expected greater attention in this regard. Instead, I had to rely on an external person, whom I paid for out of my own pocket, in order to be able to attend.

It would have been more effective to work with other organisations to help students with disabilities from a practical perspective, because not all students are familiar with all the tools needed to be independent during lectures or can physically access or use all the services provided by the university. (Sofia)

Why independent living is urgent for us and what is at stake in our lives right now

Because for me it means that I can choose my place, but right now I still cannot because now I'm living in the dormitory. (Alessia)

For me, at 26 years old, with very little motor autonomy and a very severe disability, the most important problem is being able to find a way to live with support that is different from the binary options: either staying with my family for as long as my mother is still there, or being institutionalized, or living in a residential community. Independent living is, for me, an urgent need — as the possibility of becoming and being an adult who participates in and is included in political, civil and social life, without my difference being treated by society and by the rules and regulations as a cross-cutting and irreducible limitation. (Carlo)

Because I want to be like able-bodied people and to ensure that people with disabilities have the same starting point as able-bodied people. Right now, the main challenges for me in terms of independence are moving out of my parents' house getting my own place, growing my Dreambyrage business, and having a romantic life. (Arthur)

Needing help doesn't mean I always need someone to help me. That would limit my abilities, making my disability feel like a greater burden and making everyday life more difficult. So, wherever possible, I'd like to be able to carry out activities independently. (Sofia)

2. The Legal and Normative Framework

“There is no real inclusion, independence, or autonomy without freedom.”

— *Sofia, Italy*

2.1 What Independent Living Means: The UN Definition

The right to independent living is not about living alone, nor about doing everything without support. According to CRPD General Comment No. 5 (2017, para. 16a), independent living means that ‘individuals with disabilities are provided with all necessary means to enable them to exercise choice and control over their lives and make all decisions concerning their lives.’ It encompasses every dimension of a person’s existence: where they live, with whom, how they spend their time, what work they do, whom they love.

Crucially, Article 19 applies to all persons with disabilities, irrespective of the nature or severity of their impairment, their level of intellectual capacity or the amount of support they require (GC5, para. 20-21). The right cannot be denied on the grounds that a person ‘needs too much support’ or is ‘unable to decide for themselves.’ As the ENIL/Inclusion Europe fact sheet on independent living for people with intellectual disabilities (2018) makes clear, even people with complex support needs and communication differences express preferences and exercise choices — the obligation of States is to provide the means and the support structures that make this possible for everyone.

General Comment No. 5 also provides a critical definition of what constitutes an institution (para. 16c): not only large residential facilities, but also small group homes of five to eight people, if they exhibit defining elements of institutionalisation — obligatory sharing of assistants, lack of control over daily decisions, isolation from the community, rigidity of routine irrespective of individual preferences. This definition is essential to prevent so-called ‘deinstitutionalisation’ from merely shifting people from large to small institutions without genuinely realising their rights.

2.2 The International Human Rights Framework

The right to independent living is rooted in a network of interconnected international obligations:

- Article 19 CRPD — Living independently and being included in the community: the three pillars of freedom of choice of residence, individualised support services, and accessible community services.
- Article 12 CRPD — Equal recognition before the law: the right to legal capacity, and the transition from substitute decision-making (guardianship) to supported decision-making, which is a precondition for exercising the right to independent living.
- Article 29 CRPD — Participation in political and public life: the right to vote, stand for election, and participate in civil society, which is the specific focus of the KEEP DRIVEN project and cannot be exercised without independent living.
- Articles 24, 27, 28 CRPD — The rights to inclusive education, work and employment, and an adequate standard of living, all of which are directly dependent on independent living arrangements.
- Articles 14-16 CRPD — The right to liberty and freedom from violence: institutionalisation is identified by the CRPD Committee as a form of deprivation of liberty and a context where violence, exploitation and abuse are systematically more prevalent.

The OHCHR Thematic Study on the right to live independently and be Included in the Community further identifies five structural barriers that persist across States: lack of community-based services, continued investment in institutional care, absence of personalised support, physical and informational barriers, and the dominance of the medical model of disability that treats individuals as 'objects of care' rather than rights-holders. The HRC Resolution 26/20 (2014), which established the mandate of the Special Rapporteur on the rights of persons with disabilities, reaffirms that these barriers constitute violations of international human rights law and that States have an immediate obligation to begin addressing them.

2.3 The European Framework and the Regulatory Gap

At European level, Article 26 of the EU Charter of Fundamental Rights recognises the right of persons with disabilities to benefit from measures ensuring their independence, social and occupational integration, and participation in the life of the community. The EU ratified the CRPD in 2011, making it the first international human rights convention the EU joined and binding it under EU law.

The EU Strategy for the Rights of Persons with Disabilities 2021-2030 (Union of Equality), built around the three pillars of Full Inclusion, Union of Equality and CRPD Implementation, and the European Commission's Guidance on Independent Living (November 2024) represent genuine policy advances. The Guidance explicitly acknowledges that EU funds must not be used to renovate or build institutional settings and calls on Member States to develop time-bound deinstitutionalisation strategies. The European Parliament's resolution of December 2022 'Towards equal rights for persons with disabilities' urges Member States to phase out institutional care, and the EMPL Committee's report of November 2025 on the EU Disability Strategy post-2024 calls for ESF+ to be used in full compliance with the CRPD.

The Critical Gap: Why a Directive is Needed

Despite this political momentum, a fundamental legal gap remains: there is no binding European instrument setting minimum standards for independent living. The Guidance is a Commission Notice — it has no binding legal force. The Strategy is a political document. EU Regulations prohibit the use of structural funds for institutional care, but enforcement is inconsistent: EU funds continue to flow into institutional settings in several Member States.

Without a Directive, the right to independent living depends entirely on the political will and financial capacity of the Member State — or even the region — where a person happens to live. A person with a disability moving from Latvia to Italy, or from a progressive northern Italian region to a less resourced southern region, may lose access to the very services on which their independence depends. This is incompatible with the principle of free movement and the equal enjoyment of EU citizenship. As the Joint Submission by EDF, ENIL, Inclusion Europe and Mental Health Europe to the draft General Comment No. 5 states: independent living is a precondition for the enjoyment of all other rights under the Convention.

3. The Problem: Evidence from Europe and Our Countries

3.1 The Broader European Picture

Across the European Union, the right to independent living remains profoundly unequal. Despite all 27 Member States having ratified the CRPD and many having adopted national disability strategies, the practical reality for persons with disabilities varies enormously depending on where they live.

Key Data for Europe

- More than 1 million persons with disabilities under 65, and more than 2 million over 65, still live in institutional settings across EU27 (European Commission Guidance, November 2024).
- The Eurofound 2024 report 'Paths towards independent living and social inclusion in Europe' shows that, across 24 Member States where comparison over time is possible, institutionalisation increased by 29% over the past decade.
- 28.4% of persons with disabilities in the EU are at risk of poverty or social exclusion — compared to 17.9% of non-disabled people (Eurostat/FRA 2024).
- The disability employment gap stands at 21.5 percentage points (50.6% vs 74.8% employment rate for non-disabled people). Without independent living, employment is severely restricted.
- The EU average participation in education and training is 20.4%, but national figures range from 16.3% (Italy) to 23.4% (France), revealing structural inequalities in access to lifelong learning.
- Only 24 out of 43 Council of Europe countries have any form of deinstitutionalisation strategy; of those 24, nearly 90% are described by ENIL members as either inadequate or requiring significant improvement (ENIL Independent Living Survey, 2024).
- EU structural funds (ESF+, ERDF) have in several Member States been used to renovate institutions rather than develop community alternatives — a direct violation of CRPD principles and of the conditions attached to EU cohesion funding.

The Nordic countries — Sweden, Finland and Denmark — have historically achieved the greatest progress in deinstitutionalisation, with well-funded personal assistance schemes and low rates of institutional care. In contrast, several Central and Eastern European countries continue to rely heavily on large residential institutions, in some cases housing hundreds of people. Western European countries present a mixed picture: Germany and

the Netherlands have developed personal assistance frameworks, but access varies significantly by region. Spain has made legislative advances but struggles with uneven implementation across its autonomous communities.

Across all contexts, three structural failures emerge consistently: the lack of a binding EU definition of ‘institution’ and ‘personal assistance’; the absence of common minimum funding standards; and the misuse of EU structural funds to maintain rather than dismantle institutional care.

3.2 The Situation in Our Countries

The three countries of the KEEP DRIVEN project illustrate precisely how the absence of a binding European framework produces radically different outcomes for persons with disabilities, even within the same EU legal context.

Italy

Italy has built a progressively more ambitious legislative framework for independent living: from Law 162/1998 (personalised support plans and home care), to Law 328/2000 (which established the Individual Life Project — ‘Progetto di Vita’ — as a person-centred planning tool co-designed with the individual), to Law 112/2016 ‘Dopo di Noi’ (which introduced financial safeguards for people without parental support, promoting community-based living and ‘emancipation programmes’), to the structural reform of Legislative Decree 62/2024 (driven by PNRR commitments, introducing a unified assessment system and mandatory Individual Life Projects with a ‘Project Budget’).

However, the gap between legislation and implementation is severe. Despite these laws, institutionalisation has increased by 36% over the past decade. The nationwide implementation of the Legislative Decree 62/2024 reform has been postponed to January 2027, with only 20 provinces involved in the pilot phase — creating a de facto ‘two-tier’ system of rights depending on one’s region of residence. Strong regional disparities persist: the Lombardia model (based on vouchers, the ‘Progetto di Vita’ and Case Managers, governed by Regional Law 25/2022) and the Toscana model (based on direct cash grants of up to €1,200/month for personal assistants, under DGR 753/2024) illustrate how dramatically different the practical exercise of the right to independent living can be even within the same national system.

Critics from FISH, ENIL Italia and AVI Toscana raise three specific concerns: the ISEE income test used in Toscana makes access to funding conditional on family wealth, treating independent living as a welfare benefit rather than a right; the medicalised assessment processes in many regions reduce personal projects to clinical evaluations rather than life planning tools; and the lack of structural funding means that the reform risks reshuffling existing resources rather than genuinely expanding access.

France

France enacted its landmark disability legislation with the Law of 11 February 2005 on ‘L'égalité des droits et des chances, la participation et la citoyenneté des personnes handicapées’, establishing legal recognition of the right to compensation for disability-related disadvantages. Financial support mechanisms including the Allocation aux Adultes Handicapés (AAH, providing income security) and the Majoration pour la Vie Autonome (MVA, supporting housing costs for those living independently) provide important financial foundations. Participation in education and training at 23.4% exceeds the EU average.

Yet France records the most alarming trend of the three countries: institutionalisation has increased by 101% over the past decade — the highest rate among KEEP DRIVEN partner countries and among the highest in Europe. This reveals a deep contradiction between the law's stated ambitions and its implementation. Structural barriers to independent living persist particularly for people with complex support needs, and there remain significant gaps in the availability of personal assistance services outside institutional settings.

Latvia

Latvia presents a contrasting and instructive trajectory. Grounded in the 2002 Social Services and Social Assistance Law (Latvijas Vēstnesis n. 168/2002) and the 2010 Disability Law ('Invaliditātes likums'), the Latvian system has undergone significant deinstitutionalisation efforts driven largely by EU structural funds. Municipalities are legally required to provide a minimum set of services including home care and community-based group housing. As a result, Latvia is the only KEEP DRIVEN country to have recorded a reduction in institutionalisation — down 12% over the past decade. Participation in education and training at 20.8% is close to the EU average.

However, the strong reliance on EU funding (ESF+) rather than stable national budget allocations raises serious concerns about sustainability. If EU funds are reduced or redirected, the entire progress achieved could be reversed. Moreover, significant disparities persist between urban and rural areas. The Latvian experience demonstrates that deinstitutionalisation is achievable — but it requires stable, long-term political and financial commitment that cannot depend solely on external funding cycles.

What These Three Stories Tell Us

- Despite having ratified the CRPD and adopted national legislation, all three countries show significant gaps between rights on paper and rights in practice.
- Progress in one country (Latvia) does not automatically spread to others: it requires deliberate policy choices backed by stable, long-term funding.
- The absence of binding EU minimum standards means that a person with a disability in Latvia may enjoy rights denied to their counterpart in France or Italy — and vice versa, depending on the specific right in question.
- National legislative progress can coexist with dramatic regional inequalities: Italy's internal disparities between Lombardia and Toscana illustrate that even within a single country, a binding national framework is not sufficient without enforceable minimum standards and adequate resource allocation.
- A European Directive is the appropriate tool to establish a binding common floor of rights across all Member States — and to prevent regression where progress has been made.

From your experience in your country: what does NOT work today for people with disabilities who want to live independently?

What does not work today in my country is the efficiency of social services in helping people with disabilities. We don't receive orienteering and we don't know what we can and cannot ask. (Alessia)

Some funding is provided, but it is insufficient — so that assistance becomes a collage of a few scattered moments of freedom. Allowances are based on income, creating a disillusionment from the outset: a person with a disability who wants assistance must not work. This devalues, in advance, the person's skills and abilities, their desires and their possibilities of choice — treating them instead as a span of time between diagnosis and total clinical deterioration. The family is taken for granted as the one that will take charge of the person with a disability, with little or no recognition of how exhausting the psychological and physical burden is, thereby delegating the matter to a family sphere of private drama. (Carlo)

1. Access to one's own housing

In my country, France, there has been a law in place since 2005 requiring 100% accessibility in new housing. In 2018, this requirement was lowered to 20%, which makes finding housing and living independently more difficult for me and for other people with disabilities I know.

In the absence of a sufficient number of adapted housing units, the only remaining solutions are a few rare inclusive community housing projects or living in a specialized residential facility, even though the trend is toward deinstitutionalization.

2. Social life

For the reasons mentioned above, people in wheelchairs like me can't go just anywhere, especially to friends' houses in the evening, and it's hard to insist that the parents with whom we're forced to live always host gatherings at home. It's even harder to invite people we've just met and don't know very well. (Arthur)

I already answered to this question before talking about my university experience, but I would like to add that in my country unfortunately and some services are not provided in the same way across the regions. (Sofia)

Our stories

How lack of support prevents us from studying, working, choosing where we live and participating in our communities

“I just explained how difficult it is to live where I want to because of the lack of accessible housing and the impact on my social life.

I mentioned earlier how difficult it is to be effective at work when a mobility disability slows me down.” (Arthur)

“To go to university I need to be accompanied and to have the accompaniments I should book them one week before and it happened that I forgot to book so much time earlier and so the university denied me to attend my lessons.” (Alessia)

During my university years I attended fewer and fewer lectures and seminars, having to choose certain options for convenience rather than for interest, because there was no physical help to take part in the activities — to be helped to take off and put on my jacket, to go to the canteen or the bathroom, or to be repositioned correctly. I met similar difficulties in looking for work and in taking part in community life. All of this turns into an environment of strain, rather than a chance for exchange, experience and well-being. Having always to claim my participation has often made me feel like an intruder, or a self-invited guest where I had once been a participant. (Carlo)

I already explained explain it with previous questions. (Sofia)

4. Why Now: The Political Window of Opportunity

“More accessibility = less need for accommodations = lower long-term costs.”

— *Arthur, France*

The current moment offers a unique and time-limited opportunity for European action. The EU Disability Rights Strategy 2021-2030 is at its midpoint review, and the preparation of the post-2030 strategy has already begun. The European Commission adopted the Guidance on Independent Living in November 2024, establishing political will at the highest level. The Multiannual Financial Framework (MFF) 2028-2034 is under negotiation: the rules governing ESF+ and cohesion funds must be set now, and they must explicitly prohibit the use of EU money for institutional care.

The European Parliament has already shown its readiness to act: the EMPL Committee’s report of November 2025 on the EU Disability Strategy post-2024 calls for the ESF+ to be maintained as the main instrument for social inclusion and for Member States to use it in compliance with the CRPD. The Disability Intergroup, the EMPL Committee (chaired by Li Andersson, The Left, Finland), and key MEPs including Stelios Kympouropoulos (EPP, Greece) and Katrin Langensiepen (Greens/EFA, Germany) have demonstrated cross-party commitment to the cause.

The economic argument for action is also compelling. Contrary to the perception that deinstitutionalisation is costly, the evidence shows that institutional care is often more expensive in the long run than community-based support. When persons with disabilities can live independently, they can also work, pay taxes, contribute to their communities and reduce their dependence on passive welfare benefits. The disability employment gap — currently 21.5 percentage points across the EU — represents an enormous cost in untapped human potential and lost economic output.

As young people with disabilities, we are also the bearers of the CRPD’s promise for the future. The HRC Resolution 26/20 (2014) establishing the Special Rapporteur on the rights of persons with disabilities specifically mandates the promotion of the rights of persons with disabilities as equal members of society. Article 29 CRPD — the right to participate in political and public life — is the specific lens of the KEEP DRIVEN project. We cannot participate in democracy if we are locked in institutions. We cannot vote, organise, campaign or lead if we do not control our own lives. The right to independent living and the right to democratic participation are inseparable.

Why is this urgent for you right now?

It is very urgent to give people with disabilities the right to not anticipate so much of their needs. (Alessia)

The issue is urgent precisely because some things change while others stay behind — and institutionalization, or the recourse to paternalistic forms of welfare dependency, remain the option for fixing the problem after the fact. In this sense, the advances of present-day medicine and technology create an illusion of equality: one that, if it is not guaranteed by a legal ground that truly protects the inclusion of the person with specific needs, leaves the solving of problems to the private sphere — creating or deepening the differences and inequalities between people, digging an ever-deeper furrow in the double standard between those who have fewer resources (physical, economic or social) and those who come closer to a standard. Because what is the point of developing a self-driving wheelchair, if no one sits me in it?

Moreover, formal accessibility is different from real experience. Making the environment liveable must be a central concern — but it cannot replace, nor push into the background, the possibility that the person who is supposed to live in that environment can actually do so as something normal, and not as an exception. What is the point of making an environment accessible, if I do not have the help to leave my house and reach it? In this sense, the idea of well-being and quality of life must be added to the idea of a life path — and not reduced to mere clinical survival.

All of this, then, becomes extremely urgent if it keeps being just a point on an agenda, and words become abstractions — hypostatized, and not grounded in reality. What is the point of a written right, if it remains an exception granted to a few and not a guaranteed condition?

In my life, every single day, the risk is that all these questions remain merely rhetorical — written while struggling to move my fingers. (Carlo)

It's urgent for me to have my own place because I'm an adult. I hope to soon find an accessible home thanks to my involvement in a project over the past five years. (Arthur)

As I said before limiting accessibility means limiting my freedom and if the constant reminder of the things that I can do or opportunities I miss. I want to underline it because I already know that I have limitations and even if I don't always face this situations seriously I don't need to be reminded about them every single day because of the environment I live in. (Sofia)

5. Our Vision: What Independent Living Looks Like

“Independent living is a tool of freedom — not freedom from dependence, but the freedom to choose whom I depend on.”

— *Carlo, Italy*

Independent living does not mean living alone. It does not mean refusing support. It means having the same degree of choice, control and freedom as any other citizen — and having access to the individualised support structures that make those choices real. As ENIL defines it, independent living is ‘the daily demonstration of human rights-based disability policies.’

For people with intellectual disabilities, independent living means having the right tools, the time and the accessible information to make real decisions about their own lives — with support if needed, but with authority. As the ENIL/Inclusion Europe Fact Sheet (2018) makes clear, even people with complex support needs exercise preferences and demonstrate choices: the obligation is not to decide for them, but to create the conditions in which their choices are heard, respected and supported. The Achieving Quality report (Inclusion Europe, 2003) identifies the dimensions of quality of life that matter most to people with disabilities themselves: emotional well-being, community inclusion, self-determination, personal development and civic equality. These must be the benchmarks of any independent living framework.

For us, the young participants of KEEP DRIVEN, this means being able to choose the school we attend, the job we pursue, the city we live in, the friends we spend time with, the political candidates we vote for. It means being able to move freely between EU countries without losing our support services. It means being treated as rights-holders, not as objects of care.

Our vision

How would our lives be different if a European Directive on Independent Living existed and what would change for us, for our families, for the people we know

“If there were a European directive, I hope I would find it easier to secure accessible housing to try out independent living, and that I would receive an increase in personal care hours without too long a wait.

In short, I would be starting from the same starting line as able-bodied young people who are beginning to learn independence, beyond the specific challenges associated with disability.” (Arthur)

“It will be easier to ask for help or assistance in my life, also my family will be relieved from bureaucracy and the people with disability that I know will benefit from the serenity of an easier and more independent life.” (Alessia)

The right to independent living would be regarded as a right, and not as an exception outside the norm — placed on the shoulders of the individual’s extraordinariness, in its condescension of privilege, of charity, or of class. (Carlo)

I hope that, with this directive, the European Union will give governments across all countries the practical tools to ensure that accessibility in public places is guaranteed as far as possible. These practical tools should not only concern funding but also infrastructure; should we find ourselves in a place where accessibility cannot be guaranteed, I expect to find staff willing to lend a hand without judgement. Also, I would like all people with disabilities who are able to do so to be guided on the path to achieving an independent life without relying too heavily on their families, who already look after them constantly, without any assistance. (Sofia)

What independent living means to us

The empowerment in life. (Alessia)

The freedom of choice. (Arthur)

A stable ground on which I can build myself and grow as a person and as a citizen — meeting everyday difficulties, like everyone, and to a degree appropriate to my medical condition, but without those difficulties becoming the whole of my living space. Independent living is a tool of freedom: not freedom from dependence, but the freedom to choose whom I depend on. (Carlo)

“Having a simpler life.” (Sofia)

6. Our Demands and Recommendations

We present the following recommendations, structured by the level of action required and the body to which they are addressed. They are informed by the framework established by the CRPD, General Comment No. 5, the OHCHR Thematic Study A/HRC/28/37, the Joint EDF/ENIL/Inclusion Europe/MHE Submission on GC5, the EU Disability Rights Strategy 2021-2030, the EU Commission Guidance on Independent Living (2024), and the lived experience of the project participants.

6.1 To the European Parliament: Exercise the Right of Initiative

We call on the European Parliament to exercise its power of initiative under Article 225 TFEU, requesting the European Commission to submit a formal legislative proposal for a European Directive on the Right to Independent Living. Specifically, we call on:

EP1

EMPL Committee + LIBE Committee (joint report)

Launch a Legislative Initiative Report (INL) under Article 225 TFEU, drafted as a joint report between the EMPL and LIBE Committees to maximise political weight and legal grounding. The report should outline why current EU legislation is insufficient and what the Directive should contain.

EP2

Disability Intergroup

Use its partnership with the European Disability Forum (EDF) to build broad cross-party political support for the INL, ensuring that MEPs from EPP, S&D, Renew, Greens/EFA and The Left formally co-sponsor the request.

EP3

European Parliament Plenary

Adopt the INL by absolute majority, as required by Article 225 TFEU, to give the request binding legal weight. Link the vote to the European Independent Living Day on 5 May to maximise public visibility or on 3 December the International Day of Persons with Disabilities.

EP4

European Parliament + Council

Ensure that the ESF+ Regulation for the period 2028-2034 contains explicit, enforceable provisions prohibiting the use of cohesion funds for the construction, renovation or expansion of institutional settings, and conditioning disbursement on the adoption of national deinstitutionalisation strategies with binding timelines and dedicated budgets.

6.2 To the European Commission: Propose a Binding Directive

We call on the European Commission (DG EMPL, Commissioner for Equality) to respond to the Parliament’s Article 225 request by submitting a formal legislative proposal for a Directive on Independent Living containing the following minimum elements:

EC1

European Commission

Establish a legally binding common definition of ‘independent living’, ‘institution’, ‘personal assistance’ and ‘deinstitutionalisation’, aligned with CRPD General Comment No. 5 (para. 16) and the European Expert Group’s definition of institutional care (any residential care where people are isolated from the community, lack control over decisions, and where the requirements of the organisation take precedence over individual needs).

EC2

European Commission

Set binding minimum standards for self-directed personal assistance, ensuring that: funding is allocated to the individual (not to the institution or service provider); the person with a disability has the right to recruit, train, direct and dismiss their assistant; there are no income-based eligibility tests (ISEE or equivalent) that condition a human right on family wealth; and there are no cost ceilings per person that restrict the exercise of the right.

EC3

European Commission

Mandate time-bound national deinstitutionalisation strategies with concrete timelines, measurable targets and dedicated budgets, developed in genuine consultation with organisations of persons with disabilities — with particular attention to persons with intellectual, psychosocial and complex disabilities, who are disproportionately affected by institutionalisation.

EC4

European Commission

Explicitly prohibit, as a condition of EU funding (ESF+, ERDF, NRRP), the use of public resources — both national and EU — for the construction, renovation, expansion or operational maintenance of large-scale institutional settings, including those disguised as ‘group homes’ that retain institutional characteristics.

EC5

European Commission

Guarantee the cross-border portability of independent living support for EU citizens with disabilities who exercise their right of free movement within the EU, ensuring that a person moving between Member States does not lose access to personal assistance and community services.

6.3 To the Committee of the Regions and National Governments

CoR	European Committee of the Regions (SEDEC Commission) Produce an Own-Initiative Opinion on independent living that documents how regional and local authorities are spending ESF+ funds, identifies best practices from Latvia, Nordic countries and progressive Italian regions, and provides the EMPL/LIBE Committees with evidence of the technical feasibility of a Directive.
IT	National Level — Italy Ensure the full and timely implementation of Legislative Decree 62/2024 across all regions, not only the 20 pilot provinces, by January 2027 at the latest. Eliminate the ISEE income test as a criterion for accessing independent living support. Establish a permanent consultation table with disability organisations, including persons with intellectual disabilities, to monitor implementation and address resource gaps.
FR	National Level — France Adopt a national deinstitutionalisation strategy with binding timelines and dedicated budgets to reverse the alarming trend of a 101% increase in institutionalisation over the past decade. Expand the Majoration pour la Vie Autonome (MVA) and the AAH to cover the full costs of personal assistance and remove conditionalities that limit access for people with complex support needs.
LV	National Level — Latvia Ensure the long-term sustainability of deinstitutionalisation gains by transitioning from EU-fund dependency to stable national budget allocations for community-based services and personal assistance. Address the significant urban-rural disparities in access to independent living services.

6.4 To All Stakeholders: Nothing About Us Without Us

All legislative processes, policy developments, service evaluations and budget decisions related to independent living must be developed in genuine partnership with organizations of persons with disabilities — including those led by people with intellectual disabilities and people with psychosocial disabilities. This is not a request for consultation: it is a legally binding obligation under Article 4(3) CRPD. The quality of independent living support must be evaluated from the perspective of the service user, not of the service provider or the public administration (Inclusion Europe, Achieving Quality, 2003).

What MUST be in this Directive, in our view and what would change our life if it existed

Personal assistance (like accompaniments or properly for living), help on finding a house, coordinated social services that direct you on the right way, removal of architectural barriers. (Alessia)

Heavy fines for those who fail to comply with the directive, to ensure that it is effective and not merely theoretical, like France's 2005 Disability Act.

For if France were ordered to pay heavy fines—with the economic repercussions that would entail—the media and the public would react strongly to force policymakers and businesses to comply. (Arthur)

The opportunity to have adequate support for personal assistance — to be managed directly and decoupled from income — so as to live life's experiences (in their full spectrum and complexity), where disability is one characteristic among others and not merely a handicap to be survived in spite of. (Carlo)

External accessibility of services or public spaces because even if we have a personal assistance from other parents or someone else we must access to external spaces (cinemas, bars, schools, shops...) easily. Otherwise we Cannot confirm that we have the same opportunities as other people, Not only our personal space must be adapted to our needs but also the external world should take them into consideration. (Sofia)

7. Conclusion

“The world is beautiful because it is varied.”

— *Alessia, Italy*

We are young people with disabilities. We are Italian, French and Latvian, and we speak as part of a European project. We have different impairments, different support needs, different daily realities. But we share the same fundamental conviction: we are rights-holders, not objects of care. We are experts on our own lives. We have the right to think and speak for ourselves.

The right to independent living is not a luxury to be granted when resources permit. It is a binding obligation under international and European law. It is the foundation without which no other right can be fully exercised. It is the condition of citizenship itself.

We demand that the European institutions fulfil their obligations. We demand a Directive — not a guideline, not a recommendation, not a strategy. A binding legal instrument that guarantees every person with a disability in Europe the right to choose where they live, with whom, and how. A Directive that ensures that EU money is never again used to lock people away in institutions. A Directive that makes independent living not a promise, but a reality.

Our final message

What we would like to say directly to the European Commissioner and the MEPs who will read this document

“This concerns EVERYONE!

Europe’s population is aging, and more and more people need accessibility and accommodations.

A more accessible world will also benefit people with temporary mobility challenges (pregnant women or those with strollers, travelers with luggage, etc.) and those who have become disabled due to accidents and are already struggling to adapt to their new situation without their environment creating additional difficulties.

More accessibility = less need for accommodations = lower long-term costs.” (Arthur)

“Thank you for reading this document, I hope that you will take care about that topic, because it is a real social priority and I would like to add that the world is beautiful because it is varied.” (Alessia)

Our final message

What we would like to say directly to the European Commissioner and the MEPs who will read this document

For too long, the inclusion of persons with disabilities has been treated as something that will, sooner or later, happen on its own. And with it, disability itself — as if it were a state to be ignored until it disappears into the story of a few unfortunate individuals.

Instead, it is a real condition, lived every day and with many shades. This change will not happen by itself, magically — and we exist now, and our disabilities remain, and will remain.

We ask for the tools to exist with dignity, and independent living is one of these tools: it allows us to take part — in work, in relationships, in political and civic life — like anyone else.

This is what we ask you to make a right, and not a utopia. (Carlo)

Let's begin with the first point: independent living. I know many people who have had positive experiences, but I also know that this cannot happen everywhere. I understand that not every environment or situation can be fully adapted to our needs. However, if society truly wants to include us and make us feel more independent, it needs to start by giving us more freedom, because from my point of view there is no real inclusion, independence, or autonomy without freedom.

When I use the word “freedom,” I mean it as an umbrella term. I want to be able to access places, but I also want to be free in the choices I make every day in my life. I want to have access to the same opportunities that people without disabilities have, obviously with the necessary adaptations for my needs.

I cannot truly live independently if other people constantly decide what I can or cannot do because the environment around me is not accessible enough to allow me to move freely. This applies both to housing and to many other daily needs. Independent living does not simply mean receiving assistance; it means having the possibility to choose, to participate, and to build your own life with the same dignity and autonomy as everyone else.

If I cannot choose what I am able to do, with or without support, then I cannot truly feel free. And if I am not free to make those choices, then I cannot say that I am either fully included or truly independent. (Sofia)

8. Signatures

Name	Country
Arthur Tauran	France
Alessia Degan	Italy
Carlo Savini	Italy
Sofia Procopio	Italy
Sara Donati	Italy
Valentina Tius	Italy
Madara Stepina	Latvia
Marco Bosaglia	Italy
Giona Carlo Dagnese	Italy
Jeremy Laroche	France
Kristine Laime	Latvia
Adrians	Latvia
Nikoline Krista Tesluka	Latvia
Beatrice Galbiati	Italy
Mareva Tiercin	France
Gloria De Santis	Italy
Elisa Ziliani	Italy
Sarah Baalah	France
Mamadou Lamine Keita	France
Orallin Almeida	France

Name	Country
Hawa Tandia	France
Wadj Aldhubhani	France
Juliana Farronha	France
Agathe Viseux	France
Somaya Atek	France
Tom Michel	France
Alain Villefranque	France
Vija Čuma-Zvirbule	Latvia
Sofija Meļņičenko	Latvia
Līga Birzniece	Latvia
Kristers Taupmans	Latvia
Raivis Regža	Latvia
Ralfs Dumbrājs	Latvia
Reinards Ivanovs	Latvia
Oskars Treimanis	Latvia
Tīna Jansone	Latvia
Markuss Grietēns	Latvia
Daniels Brahmanis	Latvia
Anastasija Kosiha	Latvia

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