

EU money for inclusion of people with intellectual disabilities and their families

Money is not everything.

But how you spend it says a lot about what really matters to you.

The European Union (EU) and countries often say how much they value “vulnerable”, “disadvantaged”¹ people such as people with intellectual disabilities and their families. They produced many strategies and documents about it. They need to put their money where their mouth is.

The EU can play a key role in using public money for inclusion.

It does so by:

- EU budget: using the EU funds for rights and inclusion².
- State aid: allowing national public money to support inclusion³.
- Public procurement: encouraging national public authorities to buy goods, services and construction works that support inclusion⁴.

¹ “Vulnerable” and “disadvantaged” people means, for the EU, people who are more likely to be socially excluded like people with disabilities, people in poverty, older people etc.

² EU budget means the amount of money that the European Union uses. It is up to 1,074 billion euros as part of the [Multi annual financial framework](#) for 2021-2027. Part of this budget supports the rights and inclusion of people with intellectual disabilities and their families. Among other funding programmes, the European Social Fund+ dedicates 25 billion euros for social inclusion, including the inclusion of people with disabilities.

³ The [State Aid Regulation](#) allows national money to go to businesses which are considered supporting employment of people with disabilities. (Section 6 of the General Block of exemptions)

⁴ Public procurement refers to the process that the public authorities uses to buy goods, services or construction works. The supports businesses which are considered supporting employment of people with disabilities. These businesses can benefit from reserved contracts or simpler conditions in public procurement (art. 20 and 74-77) [EU Public Procurement Directive](#) supports social services which are considered supporting employment of people with disabilities.

However, money is sometimes used against the rights of people with intellectual disabilities and their families. For example, some public money is used to sustain segregation, such as institutions.

Also, there are many ways in which money can be used better for inclusion of people with intellectual disabilities.

In 2025, the next long-term EU budget will be talked about. And the discussion on the revision of laws on state aid (national public money) and public procurement (public purchases) has started.

It is time to make changes for inclusion of people with intellectual disabilities and their families.

Investing in people

It is a decisive moment for the future of the European Union.

The decisions that EU leaders take now affect the lives of people for years and decades to come.

Many leaders in Brussels talk about making Europe more competitive⁵⁶. They say that Europe needs to be stronger in business and technology to stay ahead in the world.

We do agree.

We know that the best way to stay ahead is to invest in people.

In peoples' skills, development, and inclusion in all kinds of opportunities.

“A European approach must ensure that productivity growth and social inclusion go hand-in-hand,” says the Draghi report⁷.

⁵ https://commission.europa.eu/document/download/e6cd4328-673c-4e7a-8683-f63ffb2cf648_en?filename=Political%20Guidelines%202024-2029_EN.pdf

⁶ Competitiveness means that there is a market where the buyer and seller have an equal position. It requires that strategies are created according to the supply and demand of the market.

⁷ Mario Draghi was the former Prime Minister of Italy and former president of the European Central Bank. Draghi's report is a document he has done sharing his vision on the future market of the European Union.

People cannot be left behind, segregated, excluded or discriminated against.
Because when that happens, economic growth won't be strong long-term.

It means people should get the same chances to learn, work and live in the community
so they can contribute to the economy and society.

Skills to work and live independently are also important for the economic growth.

The EU must dedicate a significant part of its money to developing peoples' skills and
inclusion.

The EU also needs to overcome barriers to economic progress such as exclusion from
education and other aspects of society, lack of public service, or poverty.

The conditions to achieve inclusion with public money

First, public money should do no harm

Money is a powerful and necessary tool to advance rights and inclusion, for example by
supporting deinstitutionalisation and community-based services⁸.

Regulations on EU Funds⁹ and other EU guidance¹⁰ encourage investment in
independent living and inclusion.

However, reports show that the EU budget and national public money continue
segregating practices like institutions¹¹.

⁸ For more information see resources of the [European Expert Group on the transition from institutional to community based care](#).

⁹ [The Common Provision Regulation](#), laying down rules of the cohesion policy funds, states "Funds should be implemented in a way that promotes the transition from institutional to family-based and community- based care". (recital 6)

¹⁰ https://employment-social-affairs.ec.europa.eu/news/commission-adopts-guidance-independent-living-persons-disabilities-2024-11-20_en

[The European Network on Independent Living \(ENIL\)](#) compiled multiple cases reporting use of money for unlawful practices.

This situation is also due to a lack of measures from EU regulations^{12,13}.

The use of public money should be conditioned to respect the rights of people with intellectual disabilities guaranteed by the UN CRPD¹⁴.

- Public money should not go to places and organisations that segregate people with intellectual disabilities. This condition should be clearly specified in laws on EU funds, state aid and public procurement.
- Track the use of money and anticipate sanctions when money is used against the rights of people with intellectual disabilities.
- Provide more guidance and training for those who manage and use public money to properly understand the rights of people with intellectual disabilities and the kind of measures that need to be supported¹⁵.

Public money should not be used for:

- Institutions.
- Practices which support the institutional culture segregating people with intellectual disabilities and prevent them from being fully part of society.
- Practices which support substitute decision-making and deprive people from their right to decide.

¹² [The Common Provision Regulation](#) on EU Cohesion Policy Funds does not “expressly” forbid the use of EU funds for institutions. Then, there is a lack of means to track the use of Funds and engage sanctions.

¹³ [The State Aid regulation \(General Exemption Block\)](#) allows public subsidies to be allocated to sheltered employment (see SECTION 6). The [public procurement directive](#) also provides advantages for public purchases done with sheltered workshops (see article 20). This can worsen segregation if there is no way to ensure proper working conditions and rights, real pay and pathways to inclusion.

¹⁴ For example, [General comments n°5](#) of the UNCRPD Committee states “States parties should ensure that public or private funds are not spent on maintaining, renovating, establishing building or creating any form of institution or institutionalization” ... “States parties must take deliberate and immediate steps to reallocate funding towards realizing the right of persons with disabilities to living independently in the community.” (point 51)

¹⁵ The [EU Guidance on independent living](#) in the context of EU Funds is a good example.

Participation

How public money is spent should be decided in collaboration with those whose lives are impacted by it.

That means, specifically, people with intellectual disabilities should participate in debates and decisions about how EU money is spent.

Their expertise will help public authorities make better use of money.

This expertise will also help to achieve their objectives.

People with intellectual disabilities and their representative organisations need to be involved in the design, management, monitoring, and evaluation of EU money.

However, people with disabilities and their representative organisations are not being involved enough when it comes to the use of public money.

Participation remains inaccessible for people with intellectual disabilities.

Information is not provided in easy-to-understand ways.

To make sure that people with intellectual disabilities are involved in decisions about the use of public money the EU should:

- Concretely request the participation of disability organisations in regulations regarding EU Funds, public procurement and state Aid.
- Provide measures so they can effectively participate in consultations.
- Specify in the regulation that consultations must be accessible.
- Provide funding for self-advocacy and other disability organisations to take part in this work at national level.

Spread the (good) work

EU money helps good programs such as community-based services, supported employment or supported decision-making models.

These programs need to be funded and assisted in such a way that leads to sustainable, replicable¹⁶ and universal impact in the country.

This means the use of specific objectives, timelines, and success indicators for copy and expansion of programs that successfully support inclusion.

Sometimes available public money is used only with a view to being used.

Sometimes indicators like the “best value for money” and “number of beneficiaries”¹⁷ are prioritised over quality and inclusion¹⁸.

Sometimes public money goes to big organisations or consulting firms who have a lot of resources but do not work with people.

At the same time, organisations working for rights and inclusion are facing financial insecurity. They often have to operate on short-term project budgets, with no perspective after the project’s end.

Effective use of public money suffers from a lack of evaluation to what effect it’s used.

Too often, there are no indicators to determine good or bad use of public money.

There is often no mechanism to improve spending, no sanctions if the money is used against the rights and inclusion of people with intellectual disabilities.

No way to learn about the good results, and replicate them.

To make sure that the use of money is effective the EU should:

- Specify in the regulations that EU money should be used based on policies and decisions made in collaboration with people with intellectual disabilities.

¹⁶ replicable means it can be copied

¹⁷ Beneficiaries mean the people that get the money.

¹⁸ In 2015, [Inclusion Finland complained in front of the European Parliament that the implementation of the public procurement directive had led to discrimination based on disability](#). The Finnish public authorities prioritised the “best price value” over quality of support which had led to violations of human rights.

- Base the use of EU money on clear objectives, timeline, and success indicators¹⁹.
- Track public money to know its positive or negative impacts on the lives of people with intellectual disabilities and consider progressive measures.
- Collect data on / Research how EU regulations impact the use of public money for the inclusion of people with intellectual disabilities.

Simplification

It can be difficult to have access to EU Funds, do public procurement, or to justify a state aid.

EU regulations are complex.

The procedures and administrative limitations can be time-consuming and require lots of resources.

Even public authorities managing public money are sometimes not willing to use the full potential of regulations for supporting inclusion due to complex procedures²⁰.

This makes it especially difficult, if not impossible, for smaller organisations to reach the money to address the needs of people with intellectual disabilities.

This would especially apply to self-advocacy organisations or other organisations and groups representing people with intellectual disabilities.

Leaving them once more excluded from available resources and possibilities to improve inclusion.

To make it easier to use public money for inclusion the EU should:

- Simplify the procedures to apply for public money and use it.
- Provide funding and support to self-advocacy and other disability organisations to be able to make good use of EU money.

¹⁹ According to the [Common Provision Regulation](#), member states should provide a national framework to ensure implementation of the UNCRPD to receive EU Funds (Annexe 3). But in practice, this condition is not enough monitored, and EU Funds are still used in a way that sustains segregation.

²⁰ see the [EASPD report on Impact of State Aid on the Development of the Social Economy and on Service Providers for Persons with Disabilities](#).

What public money should be used for

People with intellectual disabilities face many challenges.

Public money can improve their situation.

We propose in this position paper some specific funding priorities to improve rights and inclusion.

These funding priorities are based on [Inclusion Indicators](#),²¹ which report on the challenges faced by people with intellectual disabilities and their families in Europe²².

Right to decide

Legal capacity is a strong maker of equality before the law and social inclusion.

By making legal decisions people can have the control over their life, like decide where to live, who to vote for, whom to marry, or how to spend money.

But, in Europe, in 11 countries legal capacity can be fully removed and the right to decide is not respected. In 16 countries legal capacity can be (partially) removed²³.

Only 4 countries fully respect the right to decide and should provide support in decision making.

In 14 countries people can be denied the right to vote because their legal capacity was removed. And in 12 countries people with intellectual disabilities are restricted to stand for elections.

Actions to be supported

To support the right to decide and the right to vote, public money should go to:

- Development and implementation of supported decision-making measures.
- Training support network, judges, lawyers and larger society on legal capacity and supported decision-making solutions.

²¹ <https://www.inclusion.eu/indicators>

²² The numbers reported are based on the Inclusion Indicators report which surveyed countries in Europe beyond the European Union. We thought it useful to have these numbers in this paper on EU money because some of the EU money goes to neighbouring countries.

²³ [Inclusion Indicators 2024](#)

- National strategies on the transition from substitute decision-making to supported decision-making.
- Accessibility of elections including accessible information on voting and political programmes
- Training of people with intellectual disabilities on political participation and right to vote.
- Adapting political institutions to make them accessible so people with intellectual disabilities can fully participate in political life, including exercising political mandate.

Independent living and inclusion in the community

More than 800,000 people with intellectual disabilities live in institutions which prevent them from being included in society.

Reports show that money is still used to fund institutions instead of being used to support independent living solutions and community-based support.

Actions to be supported

To support independent living and full inclusion public money should be used:

- As part of an effective deinstitutionalisation strategy, co-designed with people with intellectual disabilities and their representative organisations²⁴.
- Support deinstitutionalisation, independent living and the transformation of services towards community-based support adopting a person-centred approach ²⁵.

²⁴ [EU Guidance on independent living](#) recommends that:

- EU Funds are used as part of desinstitutionalisation strategy that anticipates clearly defined timeline for the overall deinstitutionalisation process.
- Analysis of investment gaps based on the outcome of individual needs assessments and a mapping of existing infrastructure, services and workforce.
- Time-bound targets and respective indicators.
- Dedicated budget and resources, including for the elaboration and implementation of individual plans for the transition to, and for achieving, independent living.
- Clear governance and division of the responsibilities of the main stakeholders implementing the actions.
- Robust and independent quality control system, including accessible complaint mechanisms available to persons with disabilities, their families or persons representing their interests.
- Monitoring tools to guide the structural reforms needed and related investments.

²⁵ [The report by UN Special Rapporteur on the rights of persons with disabilities](#), Gerard Quinn, informs on the need to transform services to enable inclusion and proposes recommendations to make it happen.

More specifically, money should go to initiatives that support²⁶:

- Closing institutions.
- Support for reinforcing life skills and autonomy, such as self-advocacy, peer support, circles of support, in particular for people leaving institutions.
- Home care services (e.g. social workers, nurses, etc).
- Personal assistance.
- Day care, including activity and leisure centres in inclusive, community settings.
- Supported living, accessible housing, housing adaptations, etc.
- Non-segregated social housing within the community, affordable housing.
- Accessibility of services and built environment, for instance accessible information in public transport, public buildings, etc.
- Social work, including counselling and advice services, including case work and appropriate referrals.
- Resident living services of a non-institutional character.
- Mental health and addiction support.
- Technical aids and assistive technologies (e.g. social alarms, communication aids etc.).
- Overcoming all the barriers to independent living and inclusion.

The European Expert Group²⁷ on the transition from institutional to community-based care also proposes a checklist to use the EU budget for independent living and inclusion.

This checklist includes concrete actions to be supported²⁸.

²⁶ Some initiatives that support independent living are also mentioned under the following indicators

²⁷ The [European Expert Group](#) is a group of organisations working together to move people that are forced to be in institutions back to the community.

²⁸ <https://deinstitutionalisation.com/wp-content/uploads/2021/07/updated-checklist-new-eeg-logo.pdf>

Housing and support

In 19 countries most adults with intellectual disabilities live with their parents.

In 27 countries few or no adults with intellectual disabilities live in their own place.

In 27 countries people with intellectual disabilities are likely to move into an institution after their parents can no longer look after them.

Actions to be supported

To support housing and support, public money should be used for:

- Building new homes and making part of them accessible and available to people with intellectual disabilities.
- Supported-housing measures, like financial support to pay for the rent and housing costs, services focused on the person and peer support.
- Support to understand information in relation to housing, in particular procedure to register for social housing.

Inclusion Europe published a report on housing for people with intellectual to know more about ideas and practices that should be supported²⁹.



²⁹ <https://www.inclusion.eu/housing-for-people-with-intellectual-disabilities-issues-ideas-practices>

Education

Many children with intellectual disabilities do not have access to education and attend ‘special education’ schools where they are segregated from other children³⁰.

This situation has a negative impact on the development of work and social skills for many children with disabilities. It makes it more difficult to find a job and friends in the future.

At least 500,000 children with intellectual disabilities are in special schools.

Over 18,000 children with intellectual disabilities are not in education.

Actions to be supported

The EU should support inclusive education and skills so people with disabilities can work and live independently in the community.

Public money should be used for:

- The development of inclusive education, for example by supporting plans in place in countries.
Money should also go to higher inclusive education³¹.
- Training of teachers on how to teach with pupils with intellectual disabilities in mainstream schools.
- Adjustment of schools and school programmes to make them accessible for pupils with intellectual disabilities and everyone.
- Educational support and assistance for students with intellectual disabilities in mainstream schools.
- Adjustments of school environments to remove physical barriers to school participation.

³⁰ <https://www.inclusion.eu/inclusive-education>

³¹ Programmes like the [Breaking Barriers](#) by Enable Scotland is the type of initiative that should be supported by public money.

Employment

Having a job does not only mean having a salary to be able to pay for everything on your own.

It is also about having purposes and objectives and creating social connections.

In 29 countries few or no people with intellectual disabilities are employed on the open labour market.

In 18 countries people with intellectual disabilities risk losing their disability benefits when they earn their own salary.

In 13 countries adults with intellectual disabilities working in 'protected employment' get paid less than minimum wage.

Actions to be supported

To support employment as a mean for social inclusion, public money should be used for:

- Supported employment and other programs integration people with intellectual disabilities into the open labour market.
- Universal reforms of protected employment towards real pay, working conditions and rights, and pathways to the open labour market.
- Developing inclusion strategies for businesses, employment services including reasonable accommodations.
Developing training of staff and personalised employment support.
- Access to education, life-long learning, and skills development for people with intellectual disabilities and their families.

Healthcare

People with intellectual disabilities face many kinds of discrimination when it comes to access to healthcare³².

Healthcare remains inaccessible and not affordable in many cases.

Some aspects of their health are overlooked like sexual health or mental health.

³² <https://www.inclusion.eu/healthcare>

27 countries report that most people with intellectual disabilities have access to general healthcare.

In 11 countries people with intellectual disabilities have no or very little freedom of choice about their reproductive health.

In 10 countries forced sterilisation is still performed.

Actions to be supported

The EU should support access to healthcare for people with intellectual disabilities.

It means that healthcare should be affordable, available and accessible.

To support health of people with intellectual disabilities public money should be used for:

- Support reforms of health systems, particularly on access to healthcare for people with intellectual disabilities.
- Easy-to-read information on access to healthcare.
- Training of healthcare professionals on how to work with people with intellectual disabilities, in particular on the right to decide in medical issues.
- Actions that raise the awareness and skills around reproductive rights and health as well as mental health, avoiding treating people with intellectual disabilities as children.

Representation

(Self-)advocacy enables the voice of people with disabilities and their families to be heard by policy makers and the broader society.

This is an essential element of democracy so everybody can be heard and participate in society.

In 13 countries our member organisations do not receive government funding for their advocacy work.

Actions to be supported

The EU should support (self)-advocacy groups, which are often non-profit organisations.

Investment is also needed to make their voices heard in decision-making.

Public money should be used for:

- Support for representative organisations and self-advocates groups.
- Support reasonable accommodations in decision-making processes, like easy-to-read and understand documentation and meetings for example.

Inclusion Europe



Inclusion Europe speaks up for people with intellectual disabilities and their families since 1988.

We advocate for equal rights and full inclusion in all aspects of life representing 20 million people with intellectual disabilities and their families.

We are a European organisation with members in over 30 countries representing in a democratic way the rights and interests of all people with intellectual disabilities and their families in Europe.

www.inclusion.eu

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