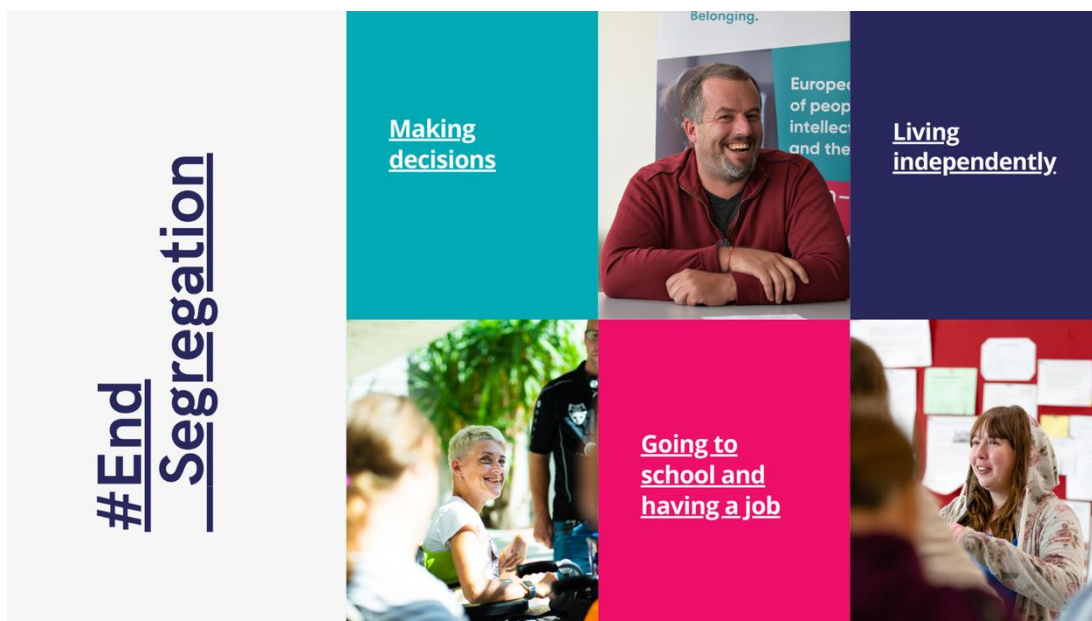


Conference report

Europe in Action to End Segregation

7 – 9 September 2022, Brussels



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Opening session

After 3 years without being able to see each other in person, Europe in Action 2022 started, bringing together Inclusion movement members and colleagues from disability NGOs and other organisations.

Jyrki Pinomaa, president of Inclusion Europe, welcomed participants.

Jyrki talked about his experience fighting to end segregation for his 2 sons with disabilities, and other people in Finland.

Jyrki presented Inclusion Europe work, mentioned our [5Es](#) strategy, and presented a new strategy to end segregation.

Jyrki's speech: ["By sharing our stories, we can help each other a lot"](#)

Elisabeta Moldovan, self-advocate from [Ceva de spus](#) / [Unloc](#) in Romania, spoke about her experience living in institutions.

Elisabeta talked about the bad treatment she suffered in those institutions.

She explained how she managed to escape from an institution.

Elisabeta is now helping other people to get free from institutions and learn to live independently.

Elisabeta's speech: ["Now I support others to get out of institutions"](#)

Cinzia Agoni, president of [GAMP](#), Belgium, shared their experience working for people with complex support needs. Cinzia has a daughter with complex support needs.

GAMP is an organisation fighting lack of support for people with complex support needs in Belgium.

They fight for independent living, through advocacy and collective complaints based on the [European Social Charter](#).

“If we manage to achieve inclusion for people with very complex needs, there will be inclusion for everyone. [...]

Fight, fight, fight.

Inclusion starts at birth, continues throughout life, and involves the whole society.”

Katarina Ivanković Knežević, director for Social Rights and Inclusion at the directorate general for employment, social affairs and inclusion of the European Commission.

Katarina spoke about the adoption of the [European Care Strategy](#), and the following steps to negotiate the text of the recommendation with Member States.

The Care Strategy proposes revision of the Barcelona targets on education, and especially early childhood care and education, with ambitious targets of enrolment in school by 2030 at least:

- 50% of children below the age of 3 are in early childhood education and care;
- 96% of children between the age of 3 and the starting age for compulsory primary education are in early childhood education and care, as already agreed in the [European Education Area framework](#).

Katarina recognised that too many people with disabilities still live in institutions.

Last year, the Commission adopted [strategy on the rights of people with disabilities](#), which pays a particular attention to independent living through two flagship initiatives:

- Guidance to Member States on independent living and living in the community for people with intellectual disabilities
- European quality framework for services, very important for people providing support for people providing services, Member States and all the different levels providing services

Katarina also referred to the situation of people with disabilities in Ukraine, and fleeing the war in Ukraine.

- With such an unpredictable situation, developing appropriate policies is a challenge, but they have been providing support through humanitarian services or different stakeholders in the neighbouring Member States.
- Neighbouring countries have been facing challenges receiving many Ukrainian refugees. Through funds like ReactEU, CARE, ESF+, but also the solidarity platform or the Temporary Protection Directive that provides access to housing, services and medical care, they have been able to provide support.
- More attention should be paid to people with disabilities.

Olena Kravchenko, chairman of the VGO Coalition, Ukraine. Chairman of organisation in Mariupol.

Olena spoke about the situation of people with disabilities in Mariupol, and elsewhere in Ukraine.

Olena's speech: [We are very grateful supported us from the first days](#)

Tetiana Lomakina, adviser of the President of Ukraine on barrier-free society, contributed with a pre-recorded message: [Message to Europe in Action participants](#)

Raisa Kravchenko, VGO coalition, Ukraine.

Raisa talked about the situation before the war, which was bad already, mothers taking care responsibilities were exhausted. The Covid pandemic made things worse.

And now the war made everything so much worse.

Olena and Raisa presented a video from the VGO Coalition to thank members of Inclusion Europe for their support and donations: [Message to Inclusion Europe](#)

Deinstitutionalisation in Czechia

Zdislava Odstrčilová, deputy minister of labour and social affairs, Czechia, provided an overview of deinstitutionalisation in the country.

Czechia has started its deinstitutionalisation process 20 years ago with several projects aiming to transform social services. These were projects funded by both EU funds and national budget within the National Strategy for Social Development. In the past, a lot was done by both the Ministry and the regions where institutions were present. Specifically, big institutions had already gone through a process of deinstitutionalisation. This process was not evaluated and therefore there are no data providing any feedback.

The deputy minister said there will be a new project in order to evaluate deinstitutionalisation in Czechia, analyse the actions undertaken until now, and create a network of experts. In particular, the Ministry would like to create experts teams which might monitor deinstitutionalisation process in currently existing but also new institutions. To reach this goal, the deputy minister highlighted the importance to collaborate with regions and also with privates, religious and charity organizations. Moreover, the deputy minister stated that Czechia aims to continue deinstitutionalisation.

Radek Rosenberger, head of social services, [CSS Stod.](#)

At the end of the 1980s the institution was composed of 9 big buildings and the institution where he was working had more than 190 men. The new director thought it was necessary to change the service. The aim was to show people in institutions the outside world: no bars at window, no uniforms and networking for staff members.

When these changes were made, they saw people could have a normal life. In 2007, they created an advocacy programme. In 2012, they opened 8 sheltered flats and sheltered workplaces, so people started to leave the institutions. They also thought that people with complex support needs had to have the possibility to leave the institution and therefore they thought of creating family houses where they could have the appropriate support.

The project was divided in 3 phases in order to avoid bureaucratic obstacles, and to use EU funds. It was finished in 2020. 107 men and women left the institutions and were relocated to 28 sheltered houses and 21 shelter flats.

Lukáš Kudlička, self-advocate, [Sebeobhájci Uherské Hradiště](#).

Lukáš grew up in an orphanage where he stayed for 18 years. He did not have the same rights as others. When he shared his will to leave, the staff started a process to strip him of legal capacity.

He wanted to live in an apartment to be more independent and learn new things. Eventually, thanks to the guardian he had, he changed and went to live in a sheltered housing. There was absolutely no preparation from the orphanage staff, like learning to cook for example.

Lukáš's speech: ["No institution can replace a proper family"](#)

Milena Johnová, councillor for health and social affairs from the City of Prague.

Mix of social service provision from NGOs, private services, local authorities and the city of Prague.

[Many missing services](#), such as respite care, support for people with complex support needs.

The journey of deinstitutionalisation in Prague started 30 years ago in Horní Poustevna. This was first supported by US funds (first half of the 1990s) and it managed to break up big institutions in small villages into smaller scale services.

In 2019, there were still many challenges in Prague to promote deinstitutionalisation because of:

- shortages of affordable housing,
- extremely long construction processes,
- staff shortages in social care
- low motivation of social care leaders

Prague [recently closed](#) one of its institutions. Key learnings from that process:

- service provision needs to move to Prague
- involvement of national level is needed
- done in 4 years (faster than typical EU-funded project in Czechia)

Sara Peskova (DG Regio), **Bianka Valkovicova** and **Olga Martinez** (both DG Empl) from the European Commission, presented how EU funds support deinstitutionalisation (namely European Social Fund +, and European Regional Development Funds).

Examples of funded actions:

- Construction of apartments for sheltered housing
- Construction of facilities for the provision of follow-up services
- Construction of facilities for the provision of ambulatory social services and field care
- Modernization and renovation of psychiatric outpatient clinics, mental health centres
- Provision of equipment for mental health centres, day centres, clinics and hospitals
- Purchase of vehicles to increase accessibility

Jan Pfeiffer, leads mental health reform at ministry of health care, talked about what changes are part of the psychiatric care reform:

- Implementation of human right as a main target
- Moving resources from institutions to Community Mental-health Centres; teams
- Reduction of current psychiatric hospitals capacity by 2/3 by 2030 (from 8,000 beds today)

László Bercse, vice-president of Inclusion Europe and chair of EPSA, shared his views on deinstitutionalisation in Czechia.

László's speech: [It is crucial to better involve self-advocates in deinstitutionalisation](#)

The session was organised in collaboration with the European Commission.

Jobs for people with intellectual disabilities

Soufiane El Amrani, Inclusion Europe's easy-to-read officer and self-advocacy expert, hosted a conversation on the importance of having a job for people with intellectual disabilities.

Pietro Vittorio Barbieri, EESC Member, President of the Thematic study group on disability rights.

PV Barbieri talked about his involvement in the field of disability.

He compares the difficulties of people with intellectual disabilities to enter the labour market to the difficulties in accessing education.

He mentions the importance of convincing other actors of the importance of inclusion, the fact that it is a fundamental right and its discrimination if not achieved.

On the recent work of the committee, it gave its opinion on the adoption of directives, for example:

- On the work with technological platforms.
- On the exploitation of workers outside the European Union.

Full speech: [Pietro Vittorio Barbieri – Jobs for people with intellectual disabilities](#)

Katrin Langensiepen, Member of the European Parliament from Germany.

She talked about the work she has been doing in Germany and also her personal story, as she has a physical disability.

When she first started as an MEP, she was the only representative with a disability. Now, there are 705 MEPs and 6 of them are people with a disability.

She emphasized the fact that there are still people with disabilities who cannot vote in their member states. A few months ago, the European Parliament voted that everyone in the EU must have the right to vote and participate in EU elections.

She mentioned that persons with disabilities are mostly unemployed and the situation for women is even worse – they receive double discrimination. And one of the key issues is the lack of statistics.

She urged that people with disabilities must have a choice and must decide on their lives.

European Parliament report on employment: [REPORT on the implementation of Council Directive 2000/78/EC establishing a general framework for equal treatment in employment and occupation in light of the UNCRPD](#)

Ana Martínez, a self-advocate from Plena Inclusion in Spain.

Plena inclusion is a Spanish organisation representing people with intellectual and developmental disabilities. Since 1963, they are present in all provinces and it is the reference NGO for people with intellectual disabilities in Spain.

In order to improve employment of people with disabilities, in Spain 2% of the positions in public administration should be for people with intellectual disabilities.

Plena inclusion created a project of public employment with the administration to make job calls accessible for the positions reserved for people with intellectual disabilities.

- Supporting the public administration in the preparation of the call for proposals
- Job analysis carried out by job coaches
- Elaboration, adaptation and validation of the syllabus in easy to read
- Validation of the syllabus by the public administration
- Agreement on the type of test, examination and modality
- Adoption and validation of the materials and support necessary for the support with easy to read

Gillian Maguire and **Brian Collins** from Microsoft spoke about Microsoft's "Supported Employment Program".

Gillian Maguire is the senior program manager for Microsoft's supported employment program and she has a background working with people with disabilities in an NGO.

Brian Collins is in charge of the supported employment program of Microsoft.

At Microsoft, they believe people with disabilities are a strength for the company to add diversity and knowledge.

To create programs for people with disabilities and have accessible spaces all over the world, accessibility has to be thought of from the start with the experience of people with disabilities.

The program helps to address the unemployment rate one job at a time. The idea was to develop a program that would partner with job coaches and the vendors at Microsoft to develop job opportunities for people with intellectual disabilities.

Also, it is important to provide training for managers and for employers.

They developed a "Knowledge centre" to engage the corporate level and managers leaders to create a safe space to ask questions and speak to experts.

The training involves people with disabilities, and job coaches.

Finally, they made their physical environment accessible.

For example, stairs have continuous handrails, there is a lot of signage with brain and high colour contrast, and there are quiet rooms and places for relaxation.

More at aka.ms/supportedemployment

Soufiane El Amrani concluded the session by saying that companies and administrations should not be afraid to hire people with intellectual disabilities, because they will learn new things from them.

Work environment needs to be made accessible for people with intellectual disabilities.

All people with intellectual disabilities must have the possibility to earn their own money like everyone else.

It is a way to gain independence and be included in the community.

Soufiane's speech: [It is important to have a job](#)

Session summary: ["People with disabilities must have a choice](#)

Watch: [Recording Jobs for People with Intellectual Disabilities](#)

The session was organised in collaboration with European Economic and Social Committee (EESC).

Practising personal future planning to realise big dreams

José Smits, from Inclusie Netherlands, with a workshop for parents and self-advocates on how to plan ahead when having a child with disabilities.

Conversations for the future

The morning of the second day was divided in focus group discussions.

The purpose was for members to learn from each other, to discuss latest work, and to develop work Inclusion Europe is doing.

Legal Capacity

Camille Latimier, director of Inclusion Czechia, leads a workshop about systemic steps to restore the right to decide of people with intellectual disabilities.

The objective of the workshop was to discuss a framework to test a system of supported decision-making in the light of Article 12 CRPD. The use of a common model with specific domains would help advancing the right to legal capacity, facilitate the exchange of good practices and build evidence base for reforms in Europe.

Deinstitutionalisation

Milan Šveřepa, director of Inclusion Europe, leads a conversation about key questions on the topic, and what Inclusion Europe members think and do about it.

The conversation looked into situation in various countries, discussed the different concepts branded “deinstitutionalisation” by various countries, and discussed how to advance the cause.

Inclusion Europe position paper will follow on this discussion, as will the newly established internal task force.

Self-advocacy

European Platform of Self-Advocates workshop about self-advocacy at European and national levels.

László Bercse speaks about EPSA activities and asks participants about how EPSA can make sure to hear the voices of people with high needs of support.

We need to learn how to communicate, to make sure we involve them in all their life decisions. He stressed that we all communicate, we just need to learn how to listen.

Ana Martínez presents the national platform of self-advocates in Spain.

She talked about all the process to have the platform, from the commitment and involvement of the boards to the training of self-advocates on leadership.

Some participants were quite interested in the training contents.

One of the participants, from Sweden, shared their journey to make sure they involved people with high needs of support on the organisation, explaining that communication is always the key issue.

Living in the Community

EPSA Steering Group wanted to ask self-advocates about what they need to live in the community, outside institutions.

For the participants it is clear that Institutions can be big or small.

When living in an institution, people can't come in and out when they want, invite people and take decisions about their lives. The services should teach about managing money, how to shop, how to cook and take care of the home. Some people may need someone to do all this, but they still have the right to live in the community.

Some of the participants, that are already living outside institutions and in the community, told us what was important for them to move out: family support, having a job, with real pay, feeling empowered and having people believing in them and training on independent living.

Family support

This session was hosted by **Kimber Bialik** from Inclusion International and **Helen Portal** from Inclusion Europe.

The session was about how social protection policies support families of people with intellectual disabilities.

We wanted to know more about the needs of family members, parents, siblings, to adjust our advocacy. Especially with the launch of the [European Care Strategy](#) and in prevision of the [30th anniversary of the International Year of the Family in 2024](#).

Participants spoke about the need for information when they learn about the child's disability, guidance on what to do, where to look for money, how to adjust their work life balance, how to get support, how to declare their care activities as work and get financial support.

One participant mentioned her dream was to have one full night of sleep.

Siblings mentioned the will to be included and the need to arrange for the future of their brother and sister when parents could no longer care. And what about solutions if there are no siblings?

We learned about different mechanisms in certain countries:

- like family planning centre in every municipality in Estonia;
- the possibility to retire at the age of 50 when you have been caring for a child with disability from the age of 6 in Ukraine, the additional 2 weeks of holidays and respite care; or
- despite good policies in Finland, they face difficulties to recruit social workers to make the system function.

Disability-inclusive rebuilding in Ukraine

Catherine Naughton, director of the European Disability Forum, moderated the conversation.

Tetiana Lomakina, adviser of the President on barrier-free society in Ukraine, spoke about the needs and priorities from the view of Ukrainian authorities.

Raisa Kravchenko from the VGO Coalition spoke about the consequences of the war on people with intellectual disabilities. The group homes stopped their services, people with intellectual disabilities needed to leave the group homes. They faced difficulties with limitations of their freedom and the change in the situation.

People with intellectual disabilities were taken to mental hospitals because they had trouble understanding the war situation and following the rules. They did not realise the danger.

Elevators were not working when there was military action, so people in wheelchairs cannot find their way to the shelter.

Now, there needs to be prevention of institutionalisation. Institutions in West of Ukraine are filling up with refugees from the East, they are now over their capacity. The burden on these institutions should be lessened and made sure institutionalisation is not encouraged. Foster family care and community care needs to be introduced.

People with intellectual disabilities are not included in the recovery plan right now, but they need to be able to fix their house, to be supported to live in the community, more funding.

Raisa's speech: [Do not use Ukraine recovery money for institutions, but for support to independent living](#)

Mariya Yassenovska from the European Disability Forum talked about the importance of inclusive rebuilding. Outside and inside areas need to be accessible to everyone, including: parking spots, guide strips on street, handrails, ramps, automated doors, stepless entrances, lifts, ramps inside, stairlift, accessible toilets, reception desks, accessible exits, shelters, emergencies exits, temporary shelters. There needs to be requirements that make buildings accessible included in the fast recovery plan.

Riga Declaration. <https://www.edf-feeph.org/publications/riga-declaration/>

Freek Spinnewijn, director of [FEANTSA](#), spoke about the close links between homelessness and being a person with intellectual disabilities, as ¼ or 1/3 of the homeless population has an intellectual disability.

Some of the reasons for homelessness are:

- displacement,
- war trauma (e.g. veterans but also civilians)

Housing affordability (800.000 houses have been destroyed in Ukraine)

Homelessness was already an issue in Ukraine but it will be increased because of the war. The concept of homelessness includes: sheltered homelessness, sofa surfers homelessness, people in very bad and very unsecure housing homelessness.

Homelessness can reinforce other problems such as mental health problems, which can in turn reinforce homelessness. Proper housing is the most important corner stone of support and deinstitutionalisation does not work if there is no proper replacement. There is no need to solve all complex needs before you provide proper housing, that is a myth.

The session was organised in collaboration with the European Disability Forum.

Inclusion index

Inclusion Europe is working on a new instrument to measure the performance of countries in Europe when it comes to inclusion.

We developed a questionnaire covering some of the important issues for our movement: education, employment, violence, right to vote, right to be elected, participation, healthcare.

During the conference, we tested the survey: 6 persons were interviewed.

They gave the general mark of 2/5 stars for the level of inclusion in their country.

They told us institutionalisation or life with parents is the reality in most countries, and so are the restrictions to vote and impossibility to be elected, the access to medical care that depends on the goodwill of the family doctor, or mostly “education” happening in special education – apart from Portugal where it does not exist anymore but it does not mean education for people with intellectual disabilities is better.

The survey will be adapted taking into account feedback from the participants.

Members exchange

Members shared among themselves what good work is happening in their organisation, and in which areas of inclusion their countries need to improve.

The key messages from the conversation are recorded in the table below.

Inclusion Europe will build on this exchange to organise trainings and other support among members.



	Things we need help with	Things we are good at
Germany	Harmonisation between States Communication Easy to read Employment in open labour market	Strong advocacy group
Belgium	Deinstitutionalisation Medical approach and psychoanalysis	Awareness for people with complex support needs Training on good practices
Romania	Deinstitutionalisation No unity between NGOs	Self-advocacy Fundraising

Slovenia	Deinstitutionalisation Legal capacity	Lifelong learning Family program Easy to read
Hungary	Right to vote Deinstitutionalisation	ETR trainings for professionals Project for women with disabilities Workshop on rights and decisions
Finland	Jobs Cooperation Legal advice	
Spain	Support for the future Accessibility Public mental health Jobs Victims of sexist violence	
Albania	Collaboration with government Sustainability of projects Networking with other NGOs Fundraising	Service provision for people with disabilities for the whole circle of their lives Advocacy and lobbying
Czechia		Agenda 2030 SDGs Advocating on all levels Opportunities for people to meet
Iceland	How to offer people jobs	“Pride” parade for disability rights
Ireland	Cost of disability Jobs Housing Inclusive education	Advocacy Easy to read Events Inclusive projects
Estonia	Finances Difficulties to reach out to politicians	Easy to read
Netherlands	Anti-discrimination law like ADA in USA	Self-advocacy (+/- 500 CRPD advocates)

Following on conversations for our future

Heather Gilchrist and **Jamie Rutherford** from ENABLE Scotland.

Heather is the membership ambassador and self-advocate from ENABLE Scotland.

She spoke about ENABLE's history of self-advocacy and their campaign to end institutional living in Scotland. She gave the example of Lennox Castle Hospital where 1,500 persons with disabilities lived.

In 2000, the Scottish Government committed to end institutionalisation, and Lennox Castle closed in 2002.

However, there are still people forced to live in hospitals and institutions because there was no right support for them.

ENABLE campaigned and in 2018, the Scottish Government identified at least 700 people in inappropriate institutions a long way from home.

Heather's speech: [It's everyone's human right to live in a home of their choice, in a community they choose, close to the people they love](#)

Jamie talked about how ENABLE Scotland provides support to people based on personal assistance model.

The Scottish Parliament passed a law in 2013 which gave everyone with a social care budget the right to self-directed care and support, but the reality has been that many people feel ill-equipped to take on the additional responsibilities that come with directing your own care and support, and so they settle for a service allocated by their local authority.

Human rights are at the centre of our PA (Personal Assistant) Model, and it makes the right to self-directed care reality for everyone who chooses ENABLE.

We do this by handling all the technical and administrative tasks that come with being an employer – such as advertising for and shortlisting candidates, payroll, people management, technology, legal and health and safety duties – while the person we work for has full control over every element of their care and support.

This means citizens can interview and make the final recruitment decision on candidates to be their PA, choose their hours of support, and choose the things they enjoy doing with their support in places they want to be with people they like to spend time with.

The ENABLE PA Model is a proven success; 88% of ENABLE’s services receive the highest wellbeing grades of “very good” or “excellent” from Scotland’s Care Inspectorate, compared to a national average of 63%; and the number of people choosing ENABLE as provider increases year on year.

Sylvia Costantini, managing director of [Revolutionise](#) talked about fundraising.

Great fundraising isn't about the size of your organisation, its history, or even your cause.

Organisations that achieve significant and sustainable income growth have very specific things in common.

It's not about what they do, it's about how they behave internally.

In this session, we'll be exploring some key behaviours needed to unlock generosity and transform fundraising income, which in turn allows your organisation to achieve much more for the people it serves.

Paul Alford, a self-advocate from Inclusion Ireland, spoke about his experience leaving institution, becoming independent by having a job in the open labour market, knowing how to manage his money, buying a house and hiring a supporter.

Paul’s speech: [Live a life of your own, get education and experience, get a job](#)

Follow-up on the conference

Task force to support advocacy-lead services

Jyrki Pinomaa and Jeanne Nicklas-Faust announced that Inclusion Europe is establishing a new task force for our members.

The aim of the task force is to support our members who provide services in developing advocacy-lead approach to service provision.

One of the task-force co-leaders will be Theresa Shearer.

Tuesday Tutorials at Two: Trainings from members, for members

To follow up on the great exchanges our members had, Inclusion Europe prepared a series of training from members, for members:

- Support and facilitate more exchange between our members
- Share experience about Inclusion Europe advocacy.

We are launching Tuesdays tutorials at Two (14.00 Brussels time).

These are 1 hour long trainings, hosted online on Microsoft Teams, for example:

- 25 October: Fundraising with Milan
- 08 November: tbd
- 15 November: Social media and communication with Inclusion Europe
- 22 November: Family support with Help the Life Association, Albania
- 29 November: Legal action for inclusion with GAMP and Inclusion Europe

These exchanges and trainings will continue in the new year and beyond.

Legal capacity

The research of Camille Latimier, Inclusion Czechia's director, who wrote her thesis on Legal capacity lead to tools on how to achieve change at micro and macro level.

The tools will be translated in English to enable all our members to use them.

Deinstitutionalisation paper

The position paper on deinstitutionalisation will conclude our 5 year strategy (Elect, Empower, Educate, Employ and End Segregation) but it will also set the tone for our new 10 year Strategy on Ending Segregation until 2030.

From this position paper will follow more detailed reports, for example on the role of families in the deinstitutionalisation process.

Inclusion index comparing inclusion in European countries

The survey to measure the level of inclusion in European countries will be updated and launched in 2023.

Future events

- Tuesday Tutorials at Two
- Hear our Voices 2023 Tallinn
- Europe in Action 2024 Edinburgh

Presentations for download:

[Presentations and Recordings Europe in Action 2022](#)

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