

Inclusion

Solidarity

Respect

Respect

Inclusion

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Solidarity

# Annual Report 2013

Inclusion Europe



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**Inclusion Europe**

Respect, solidarity and inclusion of persons with intellectual disabilities



### A LETTER FROM **THE PRESIDENT**



Maureen Piggot talks about the work Inclusion Europe did in 2013.



In 2013, we worked to make sure everyone knows about the rights of people with intellectual disabilities.

We organised different meetings and finished 2 important projects.



Maureen Piggot thanked everyone who helped Inclusion Europe in 2013.

Dear friends,

It is my great pleasure to introduce you to the 2013 annual report of Inclusion Europe which contains an overview of our main endeavours and achievements of the past twelve months.

As 2013 was the European Year of Citizens, Inclusion Europe took every opportunity to voice the expectations of citizens with intellectual disabilities and their families. During the European conference of self-advocates in October, persons with intellectual disabilities from 20 different countries spoke up and demanded their rights as citizens. Our annual 'Europe in Action' conference provided for the much-needed debate on how to ensure inclusion and quality of life for ageing people with intellectual disabilities and their families.

We are also very pleased with the results of our projects TOPSIDE and Pathways II which were finalised in October 2013. In the innovative project TOPSIDE, dozens of self-advocates were trained to support other persons with intellectual disabilities in different areas of life. Thanks to the project Pathways II, hundreds of professionals received training on how to make information and learning processes accessible to students with intellectual disabilities.

In 2013 we re-established meetings of the executive directors of our member associations. Feedback from the meetings showed the value of face to face communications in strengthening the bonds within the movement. As always, we were struck by the commonality of interests and by the creativity that is unleashed when leaders of the movement get together to share ideas and experience. This year, we have been energised by the findings from the membership review led by Inclusion International and conducted a survey of the European network that showed how the global priorities connect members through their shared concerns and through the framework of the UNCRPD.

All this would not have been possible without the relentless support of our members, experts and volunteers. I would like to take this opportunity to recognise their personal and organisational commitment which has been maintained through difficult times and to acknowledge the European Commission funding on which much of our activity depends. We look forward to working together in 2014.

Maureen Piggot  
President

### DEMANDING **EQUAL RIGHTS** AND **OPPORTUNITIES**



Inclusion Europe works to make sure that people with intellectual disabilities can use their rights as anyone else.



For example, all people with intellectual disabilities should have the right to decide for themselves.



In 2013, we organised meetings to talk about how to make sure that people with intellectual disabilities can use all their rights.



We trained self-advocates on how to support other people with intellectual disabilities in making decisions.

With 2013 as the European Year of Citizens, Inclusion Europe had plenty of opportunities to demand equal rights for citizens with intellectual disabilities in various aspects of life.

In October 2013, members of Inclusion Europe met in Brussels for a **strategic policy seminar on the implementation of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)**. The impact of the austerity measures and the involvement of persons with intellectual disabilities in the implementation of the Convention and its monitoring were the main points on the agenda.

The seminar provided for a discussion on policy changes and reforms, enabling our members to critically challenge and contribute to the work done by different institutions involved in the implementation of the Convention. A key issue highlighted by Inclusion Europe's members is the identification of evidence concerning states' progress on disability policies and their impact on people with disabilities. Legal capacity, community living and participation of people with intellectual

disabilities were repeatedly highlighted as priorities for Inclusion Europe's advocacy agenda.

#### The right to decide

Equality is only possible if each and every individual with intellectual disability is fully recognised as a person before the law. Legal capacity opens the door to full enjoyment of other fundamental rights such as the right to live independently, get married or take part in political and public life. Having legal capacity with adequate support and appropriate safeguards is thus essential for persons with intellectual disabilities to be in control of their life.

Inclusion Europe's Working Group on Human Rights and Non-Discrimination continuously supports an exchange of views and experiences on reforms of national capacity legislations. In December, the working group organised an **annual roundtable meeting of stakeholders on legal capacity and supported decision-making in Vienna**. During the event, participants looked at the role of capacity legislation and Article 12 of the UNCRPD in

# Annual Report 2013

## Inclusion Europe



*Inclusion Europe's members met in Brussels to discuss the progress in the implementation of the UNCRPD amid the economic crisis.*

supporting the autonomy of people with intellectual disabilities.

The participants had lively discussions on the discrepancies between the UNCRPD and the implementation of Article 12 by the EU Member States. The debate focused on the possibility to lobby for a comprehensive approach to legal capacity as a non-discrimination issue, and thus bring legal capacity on the EU agenda. During the meeting, our members and other disability organisations agreed that our role is to build schemes of supported decision-making by enabling persons with intellectual disabilities to make their own decisions, and having them recognised by third parties.

The roundtable was also an opportunity to discuss Inclusion Europe's **contribution to the Draft General Comment on Article 12** prepared by of the United Nations Committee on the Rights of Persons with Disabilities. A General Comment is an authoritative document on the interpretation of the UN Convention. Its adoption would be a significant step towards the realisation of the right to decide for all

persons with intellectual disabilities. In the draft version, the Committee invites the State Parties to abolish all substitute decision-making mechanisms, establish a wide range of supports for the exercise of legal capacity and involve people with disabilities and their representatives in this process.

With its work on legal capacity, Inclusion Europe also contributed to the **Global Campaign on the Right to Decide** undertaken by Inclusion International. The objective of the campaign is to identify models of support for families and individuals that enable people to control their own lives. For more information, please go to [www.inclusion-international.org](http://www.inclusion-international.org).

### Peer-support

In October 2013, Inclusion Europe finalised the European project **TOPSIDE (Training Opportunities for Peer-Supporters with Intellectual Disabilities)**. During the two years of its duration, Inclusion Europe worked together with organisations in the Czech Republic, Finland, Netherlands, Romania, Spain and

# Annual Report 2013

## Inclusion Europe



*TOPSIDE training courses equip self-advocates with the skills necessary to train and support their peers.*

the United Kingdom, to develop effective models of peer-training and peer-support for persons with intellectual disabilities.

People with intellectual disabilities often share similar life experiences. They are thus in a unique position to provide support to their peers, enabling them to take control of their lives and perform their roles as active citizens.

Based on experiences from existing peer-to-peer activities, the project created and tested a training programme with more than 150 exercises which allow trainees to develop a wide range of skills needed to support their peers. The *Guidelines for trainers* explain the methodology of the training and how it can be adapted to the needs of participants.

To help future peer-supporters understand their tasks, the project partners developed *Materials for peer-supporters* where trainees can record what they have learned. Finally, the project also created *Guidelines for mentors* whose role is to encourage and provide guidance for persons with intellectual disabilities to continue in their commitment.

During the project's lifetime, more than 50 persons with intellectual were trained to support their peers in daily life activities and decision-making. The TOPSIDE training opened the door for active participation of adults with intellectual disabilities, allowing the laureates to apply the newly acquired skills in different environments such as informal support groups, self-advocacy organisations or in counselling. For more information, please, go to [www.peer-training.eu](http://www.peer-training.eu)



*Participants of the TOPSIDE pilot training in Romania.*

### STRENGTHENING PARTICIPATION



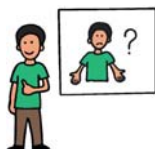
We want to make sure that people with intellectual disabilities can take an active part in society.

In 2013, we organised 2 big meetings.



In spring, we organised the 'Europe in Action' conference.

We talked about supporting older people with intellectual disabilities and their families.



In autumn, we organised a conference for self-advocates from all over Europe. They talked about their rights as citizens.



In 2013, we were also looking for ways to make sure that children with intellectual disabilities can speak up for themselves.



*Senada Halicevic, Chairperson of the European Platform of Self-Advocates, answering questions from Croatian media.*

#### Citizens first!

Over 160 persons with intellectual disabilities and supporters from 20 different countries took part in the 3<sup>rd</sup> **European conference of self-advocates** held

on 4-6 October 2013 in Zagreb. Marking the European Year of Citizens, people with intellectual disabilities took this opportunity to claim their right to participate in the European society as full and equal citizens.

Self-advocates present at the conference were unanimous in demanding the right to make choices about their own lives. They claimed their right to legal capacity as a basic precondition for their participation in all aspects of society.

People with intellectual disabilities want to have their voices heard and taken seriously. *'Don't read about us but meet with us in person. Listen to what we have to say!'* was one of the main messages addressed to European decision-makers. Self-advocates also called on governments to abolish full guardianship and invest in the development of community-based support services.

# Annual Report 2013

## Inclusion Europe



*During the conference, self-advocates could choose from a variety of 14 different workshops.*

The choice of fourteen workshops provided European self-advocates with an outstanding opportunity to discuss their rights and exchange ideas on different aspects of life.

The conference was organised by the European Platform of Self-Advocates in cooperation with the Association for Self-Advocacy and Inclusion Europe. Photos from the conference can be found at [www.flickr.com/inclusioneurope](http://www.flickr.com/inclusioneurope)

To support active citizenship of persons with intellectual disabilities, Inclusion Europe **joined the European research project DISCIT: Making persons with disabilities full citizens**. DISCIT's objective is to remove the barriers that prevent people with disabilities from participating in society and exercising their citizenship.

The project looks at the role of social services and how they meet the needs of their users. It examines the drivers of change and strategies promoting a successful move towards community living and the conditions for ensuring accessibility. It also addresses political participation and representation of persons with disabilities, including the role of disabled people's organisations in the deliberation, decision and implementation of disability policy.

Inclusion Europe takes part in the project as a member of the European Stakeholder Committee and advises on scientific and policy matters. The close dialogue between European NGOs and the research community will contribute with useful results to our policy and advocacy strategies. More information is available at the project website [www.discit.eu](http://www.discit.eu)

### Ageing people with intellectual disabilities and their families

The 2013 edition of the 'Europe in Action' conference in Ljubljana brought together a variety of stakeholders to address the challenges faced by ageing people with intellectual disabilities and their families.

The growing life expectancy of persons with intellectual disabilities is a great achievement of our time. As this is the first generation of people with intellectual disabilities to live so long, the support systems and services to guarantee their quality of life are still to be put in place.

At the conference, self-advocates, family members, professionals, experts and decision-makers discussed the concerns of ageing people

# Annual Report 2013

## Inclusion Europe



*In 2013, the annual conference of Inclusion Europe was hosted by the Slovenian association Zveza Sožitje.*

with intellectual disabilities and their family caretakers and explored the implications of their increased longevity for public policies and service-provision.

The participants highlighted the need for person-centred services to ensure inclusion, autonomy and participation of older persons with intellectual disabilities. They also called for adequate support for family caretakers throughout their lifetime, particularly when reaching old age.

The participants agreed that the lack of information and data on the situation of elderly people with intellectual disabilities was a significant barrier to policy planning and monitoring and needed to be urgently addressed.

Social policies must respond to the new situation and ensure that the necessary support services are widely available and affordable. Individualised funding was deemed necessary to ensure personalised support services for each individual.

The conference was organised in partnership with our member association Zveza Sožitje in Slovenia on the occasion of its 50th anniversary. The anniversary celebration took place during the

conference and was attended by the President of Slovenia Borut Pahor. Photos from the conference are available at [www.flickr.com/inclusioneurope](http://www.flickr.com/inclusioneurope)

### **Promoting and encouraging participation of children with intellectual disabilities**

During 2013, Inclusion Europe led the implementation of the European project 'Hear our voices'. Its objective is to develop support mechanisms for meaningful participation of children with intellectual disabilities in different aspects of community life as well as in decision-making. The project is carried out with the support of the Fundamental Rights & Citizenship Programme of the European Union, with the additional support of Lumos.

In the first year, the partnership mapped available information and collected evidence on child participation from law, policy documents and practice in order to increase understanding of how children with intellectual disabilities can be supported to effectively and meaningfully participate.

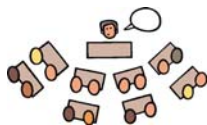
On the basis of the collected knowledge, the project partners embarked upon the development and practical testing of models of participation. These models are being tested by national partners in schools (Spain), group homes (Bulgaria) as well as with individual children in large residential institutions in the process of transition to community-based care and in local children's parliaments (Czech Republic).

In parallel to these activities, the project partners worked to increase the visibility of children with intellectual disabilities in mainstream child rights policies, legislations and practices at both national and European levels, together with our members and the members of Eurochild. For more information, please go to: [www.childright4all.eu](http://www.childright4all.eu)





In 2013, we worked to make sure people with intellectual disabilities can live independently and take part in the community.



We spoke to decision-makers in Europe and asked them to make sure that all people with intellectual disabilities can choose how they want to live.



We looked for best ways to help people with intellectual disabilities live included in the community.



In 2013, we worked to make sure that people with intellectual disabilities can get information that is easy to read and understand.

Campaigning for the right to live independently and be included in the community remained high on the agenda during 2013. While many people with intellectual disabilities still live segregated in institutions, those living in the community saw their rights jeopardised by the cuts in support for independent living.

The main framework for advocacy activities in this field was the **European Expert Group on the Transition from Institutional to Community-based Care**. We helped disseminate the *European Guidelines on the Transition from Institutional to Community-based Care* and the Toolkit on the use of EU funds to support this process. The Group organised training seminars for public authorities and other national stakeholders on the use of EU funds to support deinstitutionalisation of social services.

One of the principal achievements of the joint efforts was the inclusion of provisions referring to

deinstitutionalisation in the EU regulations setting out the rules for the use of EU structural and investment funds for the next seven years. This represents a commitment that EU funds will not be used to perpetuate institutionalisation, but to develop the much needed community-based alternatives.

#### Exploring New Paths to Inclusion

In 2013, Inclusion Europe joined organisations of persons with disabilities, service-providers, universities and research centres from thirteen European countries and Canada to work on a new European project **New Paths to Inclusion Network**.

The project builds on the learning of a former New Paths to Inclusion project (2009–2011) which helped spread the practice of Person Centred Planning in support from the United Kingdom to six other countries in Europe.

# Annual Report 2013

## Inclusion Europe

With the support of the Lifelong Learning Programme of the European Union, the New Paths to Inclusion Network helps organisations transform their services and deliver inclusive and person-centred support to persons with disabilities, as required by the United Nations Convention on the Rights of Persons with Disabilities. To make this happen, the network seeks to equip organisations and their employees with the knowledge and skills necessary to respond to the individual needs of each person with disability.

Inclusion Europe is leading the dissemination and exploitation activities of the project which shall lay foundations for a sustainable European network of person-centred support organisations. More information is available at:

[www.personcentredplanning.eu](http://www.personcentredplanning.eu)

### Enhancing accessibility

At European level, 2013 was marked by the anticipation of the European accessibility legislation. Inclusion Europe took every opportunity to highlight the accessibility needs of persons with intellectual disabilities, including the right to receive information that is easy to read and understand.

In May, Inclusion Europe's members and other organisations working on accessible information met for a **conference in Ljubljana** to share their experiences and discuss the progress done so far on improving the access of persons with intellectual disabilities to information. The participants reported that the needs of persons with intellectual disabilities are rarely taken into account when it comes to measures to increase accessibility. They demanded that the national legislation on accessibility should explicitly guarantee the provision of easy to read information.

Another issue debated at the conference was quality control of existing easy-to-read information. The involvement of persons with intellectual disabilities in its production was considered as a principal quality requirement which could not be

compromised. In light of this, the members of Inclusion Europe discussed collaboration on monitoring the use of the European easy-to-read logo in order to make sure that it only features on texts complying with the *European standards for making information easy to read and understand*.

The conference was held as a final event of the European project **Pathways II (Creating Pathways to Lifelong Learning for Adults with Intellectual Disabilities)**, carried out by Inclusion Europe and its members in Croatia, Czech Republic, Hungary, Estonia, Italy, Latvia, Slovakia, Slovenia and Spain. The project partners used the *European standards for making information easy to read and understand* and other tools in order to make information and adult education accessible to learners with intellectual disabilities.

During the two years of the project, dozens of adult education professionals received training on making information and teaching processes accessible to people with intellectual disabilities. Another series of seminars was organised for self-advocates who learned about their role in the production and quality control of accessible information. In total, some five hundred professionals and persons with intellectual disabilities received Pathways training in 2013. The project partners also met with decision-makers at national, regional and local level to discuss the need to increase accessibility of information and mainstream adult education programmes. The *European standards for making information easy to read and understand* and other Pathways tools are now available in sixteen languages on the project website [www.life-long-learning.eu](http://www.life-long-learning.eu).

In 2013, Inclusion Europe continued to produce easy to read information on its work and important European and international developments. We published four issues of **Europe for us** – an easy to read newsletter of the European Platform of Self-Advocates in English, French, German and Spanish. We also worked together with a number of international organisations to help them make their documents easy to read and understand.



## EUROPEAN PLATFORM OF SELF-ADVOCATES

EPSA work plan for 2012-2014 had 3 priorities:

- Tell others about EPSA and self-advocacy
- Build up our network
- Ensure training for self-advocates

EPSA had some set-backs in 2013.

At the beginning of the year, Anne Jorunn resigned from her position in the steering group.

Only 2 people were left in the steering group.

This was the situation until October 2013 when 2 new members were elected.

We now have 4 women in the steering group:

2 from Romania, 1 from Croatia and 1 from England.

EPSA has grown in 2013.

'Ceva de Spus' from Romania became a member at the General Meeting in Zagreb.

EPSA is still struggling to find a way of reaching its members in a more effective way.

We still find it difficult to have our members sharing with us their main achievements at national level.

We still need to find better ways of communication.

Our members are still struggling with a lack of finances.

Because of this, they have had difficulties to be more active.

The lack of information in their national languages and the lack of resources for translating information continue to be a problem. Despite our efforts we have not managed to solve this issue.

According to the questionnaire replies that we have received from our members, their main concerns for EPSA in near future are related to the communication between members and the lack of money.



Our members are also concerned with the need to have more members. Our members want us to focus on independent living, the right to have a family and to work, and to participate in public life.

Some ideas for the next 2 years are to produce a promotional video that could be uploaded to our website, to promote study visits between members and to organise again a conference for self-advocates.

Conferences for self-advocates should include opportunities to network and to socialise.

They prefer several workshops to big plenary sessions.

Although we still have room for improvement, we see that self-advocacy movement is growing in Europe. Self-advocacy organisations are very enthusiastic to take part in EPSA conferences.

In fact, more than 16 countries and 160 persons attended the 'Hear our Voices' conference in Zagreb.



### FINANCIAL REPORT 2013



Inclusion Europe did well with money in 2013.

But we still need to save more money which we could use in case of problems.



We want to thank all the people that supported our work.

In the financial year 2013, Inclusion Europe maintained again a small surplus in its operation despite the continued challenging economic environment in Europe. Furthermore, our External Auditor has again certified that our bookkeeping fully meets all Belgian laws as well as the Commission standards and requirements. Unfortunately, reserves continue to be of concern as they are too small to support our association through potential future financial difficulties.

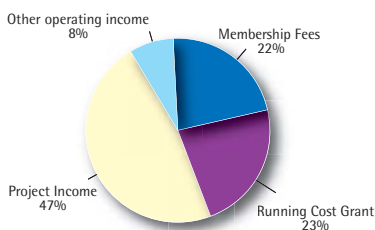
In 2013 we had an External Audit of three European Commission projects. The auditors commended on the quality of our accountancy and confirmed that our procedures and internal controls provided for good financial management of projects. Our accounting system is fully geared to ensure effective and efficient financial reporting and control of complex European projects.

As we look ahead to 2014, we expect a persistent challenging economic environment but continue our commitment to running Inclusion Europe with the necessary financial rigor and discipline in order to maintain a viable and stable financial structure.

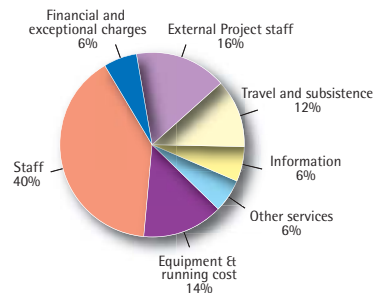
In closing, I would like to express my sincere thanks to all our members who paid their fees in 2013: this shows their high commitment to the work of Inclusion Europe. Furthermore, my thanks go to the European Commission and other funders for their continuing support for different activities at European level for people with intellectual disabilities and their families.

Hannes Traxler  
Treasurer

**Income 2013**  
646,527.51 €



**Expenditure 2013**  
644,903.62 €



# Annual Report 2013

## Inclusion Europe

### OUR TEAM



Maureen Piggot  
President  
United Kingdom

#### THE BOARD

The Board of Inclusion Europe is elected at the Annual General Assembly and is responsible for managing the affairs of Inclusion Europe.



Helene Holand  
Vice-President  
Norway



Senada Halilcevic  
Vice-President  
Croatia



José Smits  
Secretary General  
The Netherlands



Hannes Traxler  
Treasurer  
Austria



Jordi Costa Molina  
Spain



Gerard Kowalski  
France



Ingrid Körner  
Germany



Jyrki Pinomaa  
Finland



Anne Jorunn Økland  
Norway



Denise Roza  
Russia



Laura Mazzone  
Italy



Dana Migaliova  
Lithuania

#### THE SECRETARIAT

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Petra Letavayová, Communications Officer  
Luca Magri, Project Coordinator  
Sandra Marques, Self-Advocacy Officer  
Soufiane El Amrani, Easy-to-Read Editor  
Jacqueline Pareys, Office Assistant  
Daniel Scheiff, Volunteer

Trainees: Nina Karcher, Vicky McKenna and Lucia Sobeková

# Annual Report 2013

## Inclusion Europe

### OUR MEMBERS

- **Albania:** Help the Life Association
- **Austria:** Lebenshilfe Österreich / Lebenshilfe Wien
- **Belgium:** ANAHM/NVHVG
- **Bosnia Herzegovina:** SUMERO
- **Bulgaria:** Bulgarian Association for Persons with Intellectual Disabilities (BAPID) / Karin Dom Foundation
- **Croatia:** Association for Self-Advocacy / Association for Promoting Inclusion / SAVEZMR
- **Cyprus:** PASYGOKA
- **Czech Republic:** Inclusion Czech Republic / Sebeobhájci Praha / Rytmus
- **Denmark:** Landesforeningen LEV
- **Estonia:** Estonian Mentally Disabled People Support Organisation (EVPIT) / EVPIT Self-Advocacy Group
- **Faroe Islands:** Javni
- **Finland:** FDUV / Kehitysvammaisten Tukiliitto ry / Me Itse ry / Steg för Steg
- **France:** UNAPEI / Nous Aussi / Les Papillons Blancs de Dunkerque
- **Former Yugoslav Republic of Macedonia (FYROM):** Poraka / Poraka Negotino
- **Germany:** Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V / Der Rat behinderter Menschen der Bundesvereinigung Lebenshilfe / Lebenshilfe Landersverband Schleswig-Holstein
- **Greece:** POSGAmEa
- **Hungary:** Hungarian Association for Persons with Intellectual Disability (ÉFOÉSZ) / ÉFOÉSZ Self-Advocacy Group
- **Iceland:** Landssamtökin Throskahjálþ
- **Ireland:** Inclusion Ireland
- **Israel:** AKIM Israel
- **Italy:** Associazione Nazionale di Famiglie di Persone con Disabilità Intellettiva e/o Relazionale (ANFFAS)
- **Latvia:** Rupju Berns / Rupju Berns - Latvian Self-Advocacy Movement
- **Lithuania:** Lithuanian Welfare Society for Persons with Mental Disability (VILTIS)
- **Luxembourg:** APEMH / Ligue HMC
- **Malta:** Movement in Favour of Rights for Persons with Disability / INSPIRE - The Foundation for Inclusion
- **The Netherlands:** Inclusion Netherlands
- **Norway:** NFU Norwegian Association for Persons with Developmental Disabilities / NFU Self-Advocacy Group
- **Poland:** Polish Association for Persons with Mental Disability (PSOUU)
- **Portugal:** FENACERCI
- **Romania:** Federatia Includiune Romania / Self-Advocacy Group Pentru Voi / Ceva de Spus
- **Russia:** Perspektiva
- **Scotland:** Enable Scotland / Enable ACE Committee
- **Serbia:** Serbian Association for Promoting Inclusion (SAPI)
- **Slovakia:** Association for Help to People with Intellectual Disabilities in the Slovak Republic
- **Slovenia:** Zveza Sožitje / Centre Dolfke Bostjancic Draga
- **Spain:** FEAPS / Dincat
- **Sweden:** Swedish National Association for Persons with Intellectual Disability (FUB) / Rikssektionen Klippan
- **Switzerland:** INSIEME
- **United Kingdom:** Mencap
- **Europe:** European Co-operation in Anthroposophical Curative Education and Social Therapy (ECCE) / Down Syndrome Education International



## Inclusion Europe

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