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Inclusion Europe

Respect, solidarity and inclusion of persons with intellectual disabilities

ABOUT INCLUSION EUROPE





Inclusion Europe fights for the rights of persons with intellectual disabilities and their families in Europe.

Organisations of persons with intellectual disabilities and their families in 37 countries are part of Inclusion Europe.



We want to make sure that persons with intellectual disabilities have the same rights and opportunities as all other people.

We work together with organisations and politicians in Europe to make this happen.

Inclusion Europe is the voice and representation of persons with intellectual disabilities and their families at European level. Bringing together 66 organisations in 37 countries, the association fights for equal rights and full inclusion of persons with intellectual disabilities in society.

Our movement is based on the core values of respect, solidarity and inclusion. We aspire for Europe where persons with intellectual disabilities live included in the community, access the same rights as other citizens and enjoy equal opportunities to participate in education, employment, political and public life and other aspects of society.

Our work is guided by the United Nations Convention on the Rights of Persons with Disabilities which was ratified by the European Union and most European countries.

We work together with European Union institutions, the Council of Europe and other European stakeholders, mainstreaming the needs and perspectives of persons with intellectual disabilities and their families in European policy-making.

- We stimulate the exchange of knowledge and experiences concerning the implementation of the UN Convention and its specific articles.
- We support national policy priorities of our members and we provide all interested stakeholders with well-rounded and accessible information on European policies and developments.

In order to strengthen its impact on European policies, Inclusion Europe is a member of several umbrella organisations and civil society alliances, including:

- Inclusion International, a global federation of organisations of persons with intellectual disabilities and their families
- European Disability Forum, a European umbrella organisation representing the rights and interests of persons with disabilities
- Social Platform, Platform of European Social NGOs
- European Coalition for Community Living, a Europe-wide initiative promoting the development of community-based services for persons with disabilities.

A LETTER FROM THE PRESIDENT





Maureen Piggot is the President of Inclusion Europe. She talks about important things that happened in 2012.

Inclusion Europe organised a big conference to talk about the right to work.

Inclusion Europe also worked on different projects. These projects will help persons with intellectual disabilities to learn new skills.

Maureen Piggot thanked everyone who helped Inclusion Europe in 2012.

Dear friends,

2012 was a year of great challenges as well as considerable opportunities which inspired the work of Inclusion Europe. The economic crisis continued unabated, with austerity policies causing serious concern across our network about threats to rights and the loss of practical and political support for the inclusion of persons with intellectual disabilities and their families. In these turbulent times, voicing the issues and the expectations of persons with intellectual disabilities and their families at European level proved more important than ever.

Employment and active inclusion in the open labour market was the main theme of our annual 'Europe in Action' conference. Self-advocates made clear that they want real jobs for real pay; they want rights, not favours. Economic inclusion is essential for individuals to be valued equally, live independently and take control of their lives. It is, however, equally important for Europe to recognize the potential of persons with intellectual disabilities to contribute to the economic activity and well-being of their communities. Another vital element in achieving inclusion and social status is a good education, including provision for life-long learning. Within the framework of the European project Pathways, Inclusion Europe cooperated with members in nine countries to increase participation in adult education by making information accessible. We are equally proud of our innovative project, TOPSIDE, which is developing good practice in peer-training and peer-support for persons with intellectual disabilities. The project opens up opportunities for self-advocates to train and support their peers in making decisions, living independently and taking part in the community.

This annual report offers an overview of our key activities and achievements in the past year. I would like to personally thank all our members, partners and supporters for their invaluable collaboration and tireless commitment to the goals of the inclusion movement throughout the year.

Momen Rigg V.

Maureen Piggot President

ACCESS TO RIGHTS AND LEGAL CAPACITY





Inclusion Europe wants to make sure that persons with intellectual disabilities can use all the rights written in the United Nations Convention on the Rights of Persons with Disabilities.

In 2012, we organised a meeting about how disability organisations can use the Convention to fight for the rights of persons with intellectual disabilities.

There was also a meeting in Northern Ireland to talk about the right to make important decisions in life.

Inclusion Europe also started a new project. The project will help children with intellectual disabilities have a say and take part in the community.

Monitoring the implementation of the UN Convention on the Rights of Persons with Disabilities

The ratification of the UN Convention on the Rights of Persons with Disabilities by the European Union and most European countries was a major breakthrough for the disability movement. Our overreaching objective is to make sure that persons with intellectual disabilities have equal access to all the rights listed in this treaty. It is thus of utmost importance for Inclusion Europe to support the active participation of persons with intellectual disabilities, their families and organisations in the implementation of the UN Convention and its monitoring.

On 30 May 2012, Inclusion Europe organised a training seminar on how to effectively use the monitoring tools offered by the UN Convention. Organisations of persons with disabilities from different countries shared their experiences in building an NGO coalition at national level. On the basis of experiences from Belgium and Spain, the participants discussed the process of drafting the alternative report to the Committee on the Rights of Persons with Disabilities. The need to involve persons with intellectual disabilities and their families was highlighted. Held in Brussels, the training was very successful and brought together a lot of high level representatives, including Pierre Gyslinck, President of the Belgian Disability Forum and Edouard Delruelle, Vice-Director of the Belgian Centre for Equal Opportunities and Opposition to Racism.

Supporting reforms of legal capacity legislations

Full recognition of legal capacity and the development of effective models of supported decision-making are among our top priorities. Thanks to the involvement of the Working Group on Human Rights and Non-Discrimination, Inclusion Europe continued to develop concepts and policies to implement full legal capacity, access to justice and protection against discrimination.

One of the main highlights was the annual roundtable meeting of stakeholders in legal capacity and supported decision-making. During



The roundtable on legal capacity supported the advocacy activities of our members.

the event which took place on 26 November in Belfast, Inclusion Europe together with members in Northern Ireland and the Republic of Ireland challenged the administration of Northern Ireland to remove the concept of 'best interest' from the draft legal capacity bill. The notion of 'best interest' directly implies that the decisions are taken by a third person and is thus irreconcilable with the model of supported-decision making put forward in the UN Convention.

Together with the roundtable meeting, Inclusion Europe organised a study visit on legal capacity and supported-decision making. The participants attended the 'Joint All Party Assembly Group meeting' on the 'Social Care Reform' where people with intellectual disabilities, their families, carers and professionals discussed with the Minister for Health and other relevant politicians in Northern Ireland. They also met with representatives of the Equality Commission in Northern Ireland and the Northern Ireland Human Rights Commission as well as with the representatives of the Office of the First Minister and deputy First Minister, Children and Young People's Unit.

Making children's voices heard

The comparative research on the rights of children with intellectual disabilities in Europe published at the end of 2011 generated considerable interest among European and international stakeholders. In 2012, Inclusion Europe was invited to present the findings in a number of meetings which dealt with the rights of vulnerable groups of children.

With the support of the European Commission, Inclusion Europe started cooperation with Eurochild, the European NGO promoting the welfare of children and young people in Europe, and members of both networks on a European project 'Hear our voices'. The collaboration seeks to improve the participation of children with intellectual disabilities in the community and ensure their right to express their views on matters affecting them. More information about our work on children's rights can be found at <u>www.childrights 4all.eu</u>.



The project 'Hear our voices' aims to increase the participation of children with intellectual disabilities in all areas of life.

LIVING INDEPENDENTLY AND BEING INCLUDED IN THE COMMUNITY





Inclusion Europe wants to make sure that persons with intellectual disabilities can live independently and be part of the community.



In 2012, Inclusion Europe worked together with other organisations to make sure there is more support for persons with intellectual disabilities in the community.

In 2012, budget cuts continued to affect the rights of persons with intellectual disabilities to live independently and be included in the community. Against this backdrop, Inclusion Europe continued to campaign for the development of quality community-based services.

A bulk of this work was carried out within the framework of the European Expert Group on the Transition from Institutional to Community-Based Care, a broad coalition of stakeholders representing people with care or support needs as well as service providers, public authorities and the representatives of UNICEF and the Regional Office for Europe of the UN Human Rights Office (OHCHR).

The key outcome of this cooperation in 2012 was the development of the Common European Guidelines on the Transition from Institutional to Community-Based Care and the Toolkit on the use of EU funding to support this transition. Both publications are available for free download in number of European languages а at www.deinstitutionalisationquide.eu. The group also embarked on advocacy activities to influence the negotiations of the EU budget for the next seven years in order to make sure that EU funding used to support the development of is community-based services.

At global level, we actively supported the campaign of Inclusion International to promote the right to live and be included in the community. Inclusion Europe and its members contributed with a European perspective to the preparation of the Global Report 'Inclusive Communities – Stronger Communities'. Our representatives also participated in an International Forum 'Achieving Inclusion across the Globe' in Washington where the report was officially launched as the main outcome of the campaign.

Finally, Inclusion Europe worked together with other organisations to influence European authorities and ensure adequate support for the right of persons with disabilities to live in the community. We supported the campaign of the European Network of Independent Living pushing for a European Parliament resolution against the impact of budget cuts on the rights of persons with disabilities as well as the Open Society Mental Health Initiative petition against the use of EU funding to maintain the segregation of person with disabilities in isolated residential facilities.

THE RIGHT TO WORK AND INCLUSIVE EMPLOYMENT



Inclusion Europe wants to make sure that all persons with intellectual disabilities can have a real job and get real pay.



In 2012, Inclusion Europe organised a big conference about the right to work in Brussels.



People from all over Europe came to the conference. They agreed on what needs to be done so that more persons with intellectual disabilities have jobs.

Inclusive strategies to increase the participation of persons with intellectual disabilities in the open labour market were under the spotlight during our annual 'Europe in Action' conference held from 31 May to 2 June in Brussels. The conference brought together over 150 participants from across Europe and beyond, comprising persons with intellectual disabilities, their supporters, family members, professionals, public authorities and serviceproviders.

The conference acknowledged the dramatic consequences of underemployment for the economic as well as social inclusion of persons with intellectual disabilities. Despite concerns related to the uncertainties of the open labour market, the participants agreed on the urgent need to enhance active inclusion of persons with intellectual disabilities in mainstream employment. The conference showcased a number of good practices and pilot projects which provide a solid basis for moving towards a systematic approach to economic inclusion.

In light of the currently difficult economic situation, the conference highlighted the need for a gradual and sustained transition towards inclusive work settings, ensuring the availability of appropriate job alternatives in the open labour market. To make this happen, Europe needs inclusive employment policies that build a strong link between education, employment incentives and welfare system.



Vocational training, reasonable accommodation and the 'benefits trap' were among the issues discussed at the annual conference in Brussels.

The conference was organised in partnership with ANAHM/ NVHVG, a national association supporting persons with intellectual disabilities and their families in Belgium.

ACCESS TO **EDUCATION** AND **LIFELONG LEARNING**





In 2012, we worked to make sure that children with intellectual disabilities can go to school together with children without disabilities.



We also worked on 2 projects to make sure that adults with intellectual disabilities can learn new things all their life.



Project Pathways helped to make learning and training more accessible.

Project TOPSIDE trained self-advocates to support other persons with intellectual disabilities.

Education for all!

Inclusive education remains high on our policy agenda. The Working Group on Inclusive Education is the driving force behind our efforts to expand the concept of inclusive education in Europe. In a meeting held in Barcelona in September 2012, the group discussed strategies to optimize available resources and tackle the negative impact of the crisis on the progress towards inclusive education. In light of this, a new work plan was drafted whereby the Working Group resolved to work on three main objectives: recognising, networking and responding.

Recognising: The group will continue to raise awareness about the fact that, contrary to what many politicians claim, inclusive education is far from being granted. This right is guaranteed under the UN Convention which was ratified by most European countries. However, effective measures to implement inclusive education are still missing. The planned awareness—raising activities include the dissemination of articles, distribution of position papers among key stakeholders as well as participation in conferences and teacher training.

Networking: In line with its challenging objectives, the group will continue to support the collection and exchange of experiences and good practices on inclusive education in Europe.

Responding: All the work mentioned above will provide a basis for concrete action to facilitate progress towards good quality inclusive education. The group seeks to share good practices that help us to rethink the existing system, optimize resources and involve teachers.

Creating pathways to lifelong learning

Access to education and lifelong learning is essential for persons with intellectual disabilities to maintain and improve the skills they need to live independently and take an active part in the community. In 2012, Inclusion Europe and its members cooperating on the European project 'Creating Pathways to Lifelong Learning for Adults with Intellectual Disabilities' made great efforts to improve the accessibility of information and adult education programmes for this particular group of learners.

Project Pathways provided education professionals and persons with intellectual disabilities in nine European countries with a set of methodology and guidelines on how to systematically open formal education for the participation of adults with



Project Pathways brought together members of Inclusion Europe to work on accessible information and lifelong learning.

intellectual disabilities. The European standards for making information easy to read and understand, a training program for lifelong learning staff and other tools were adapted to the particular situation and language specificities in Croatia, Czech Republic, Estonia, Hungary, Italy, Latvia, Slovakia, Slovenia and Spain. Following the train-the-trainers seminar organised by each partner at national level, a number of certified Pathways trainers are available in each country to deliver training to both teachers and self-advocates on how to make information, study materials as well as the learning process itself more accessible. More information about the project Pathways is available at <u>www.life-long-learning.eu</u>.

Creating new opportunities for informal education

An innovative element in informal adult education was introduced by the European project Training Opportunities for Peer-Supporters with Intellectual Disabilities (TOPSIDE). The project develops training for adult peer-supporters that enables persons with intellectual disabilities to informally train and provide support to their peers in different life situations.

In 2012, the project partners met four times and identified the guiding principles, the values and a comprehensive set of skills to become a peer supporter. On this basis, they defined the structure and the content of the curriculum as well as the working methods. The outcomes so far include a clear vision of what the role of the peer supporter is, a profile of the peer supporter and the objectives of the training and a set of skills to be trained on, divided into three categories: peer to peer skills, inclusive values skills and pragmatic skills. The project partners have decided to create a flexible structure of the curriculum, which would allow trainers to work on a skill basis or on a topic basis. It will allow the trainer to adapt the course according to the topics that are relevant for the particular group of peer supporters. More information about the project TOPSIDE can be found at www.peer-training.eu.

Projects Pathways and TOPSIDE are carried out with the support of the Lifelong Learning Programme of the European Union.



Future peer-supporters at the TOPSIDE pilot training in Catalonia, Spain.

ACCESSIBILITY





Inclusion Europe fights for the right of persons with intellectual disabilities to get information that is easy to understand.

In 2012, we gave ideas about what should be included in a future European law on accessibility.



At the same time, we worked to make 'easy-to-read' more known in Europe. We also made easy-to-read versions of important documents.

2012 was marked by the anticipation of the proposal for the future European Accessibility Act expected to improve accessibility of goods and services in the internal market. Inclusion Europe collaborated with the European Commission and European NGOs to make sure that the future legislation takes into account the accessibility needs of persons with intellectual disabilities. We took part in consultations carried out in the preparation of such legislation. In our contribution, we put forward four key components to enhance the accessibility from the perspective of intellectual disability:

- Availability of information in easy to read and understand formats
- Availability of goods that are designed to be simple to use
- Clear orientation aids that help people to find their way
- Availability of human support in using goods and services.

In parallel, Inclusion Europe successfully disseminated the European standards for making information easy to read and understand in nine new European countries, namely Croatia, Czech Republic, Estonia, Hungary, Italy, Latvia, Slovakia, Slovenia and Spain. As a result, the 'easy-to-read guidelines' are now available as a standard framework for making information accessible in the majority of EU members states.

Furthermore we continued to provide persons with intellectual disabilities with accessible information on our work and relevant European developments. We published four issues of Europe for us – an easy to read newsletter of the European self-advocacy movement in English, French, German and Spanish. Our news website <u>www.e-Include.eu</u> is updated daily with summaries of every news item published online.

Finally, a great success on accessibility is the collaboration between Inclusion Europe and the Office of the United Nations High Commissioner for Human Rights (OHCHR). Inclusion Europe prepared an easy to read version of its thematic study on participation of people with disabilities in political and public life. It is the first time that a thematic study by the OHCHR is also available in easy to read and understand format. Similar collaboration was carried out with the European Commission, UNICEF, Human Rights Watch and the European Disability Forum.

INCLUSIVE **HEALTHCARE**





Persons with intellectual disabilities sometimes find it hard to get help when they are sick. Inclusion Europe wants to change this.



In 2012, Inclusion Europe wrote a paper explaining what needs to be done to make sure that persons with intellectual disabilities get good healthcare.

In 2012, the Annual General Assembly tackled the discrimination of persons with intellectual disabilities in the area of healthcare. The position paper which was adopted during its meeting on 1 June addressed the complex challenges encountered by persons with intellectual disabilities and made several recommendations in order to improve their access to inclusive, good quality and affordable healthcare services. The General Assembly called for:

- Consideration of the views of persons with intellectual disabilities and their families
- Provision of tools for better communication between healthcare professionals and social care

professionals to facilitate support, especially for people with complex needs

- More specific training and professional education as well as disability awareness training for health professionals
- Accessible health prevention programs and programs for positive health behaviour
- Regular survey of experiences made by persons with intellectual disabilities and their families in accessing healthcare services.

For the full account of recommendations, please, consult the position paper available at <u>http://www.inclusion-europe.org/en/more-information/position-papers</u>.



Vice-Presidents of Inclusion Europe Helene Holand and Senada Halilcevic at the Annual General Assembly in Brussels.



EUROPEAN PLATFORM OF SELF-ADVOCATES





In 2012, EPSA wanted to implement its work plan 2010-2012.

We had some difficulties.

In 2012 Andrew Doyle could no longer be a candidate in elections. Fabrice Vannobel, another member of the steering group, resigned. Krisse Paaskynnen was not able to continue as a member because the organisation did not have enough money to support him.

But we were able to grow in 2012.

Pentru Voi, a self-advocacy organisation from Romania, is now a member.

In Croatia, ASA organised more than 100 meetings with self-advocates and 2 conferences for self-advocates.

They were also actively involved in the fight to change legislation and allow persons with intellectual disabilities to vote.

Our member from Scotland organised 4 national meetings related to self-advocacy.

In England, our member lobbied for better health care for persons with intellectual disabilities.

In Estonia, our member organised 2 national meetings for self-advocates.

In Germany, 2.500 persons with disabilities were at the Parliament and spoke with politicians.

Main problems our members have are linked with lack of money. In fact, this is a big problem and we expect more difficulties in 2013.

Our members also say that they need information in their national languages.

We were not able to have them translating the materials to their national languages.

In 2013, EPSA must work harder to find solutions to the problems reported by its members.

OUR TEAM

THE BOARD



Maureen Piggot President United Kingdom



Helene Holand Vice-President Norway



Senada Halilcevic Vice-President Croatia



José Smits Secretary General The Netherlands



The Board of Inclusion Europe is elected at the Annual General Assembly and is

responsible for managing the affairs of Inclusion Europe.

Hannes Traxler Treasurer Austria



Jordi Costa Molina Spain



Françoise Kbayaa France



Ingrid Körner

Germany



Krisse Paaskynen Finland



Jyrki Pinomaa Finland



Denise Roza Russia



Anne Jorunn Økland Norway



Laura Mazzone Italy

THE SECRETARIAT

Inclusion Europe's main office is established in Brussels, Belgium.

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In 2012, the Secretariat was also supported by: Olga Radzienczak, Conference and Meetings Organiser Rocio Gomez Mugica, Information Trainee Nina Karcher, Policy Communications Trainee



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 Throskahjálp
- 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 Incluziune Romania / Self-Advocacy Group Pentru Voi
- 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 SR (ZPMPv SR)
- 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

FINANCIAL REPORT 2012





Inclusion Europe did well with money in 2012.

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

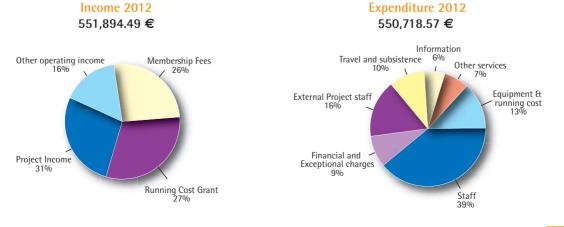
We want to thank to all the people that supported our work.

I would like to start my report with the good news that in the financial year 2012, Inclusion Europe was again able to maintain a small surplus in its operation. Furthermore, our External Auditor has again certified that our bookkeeping fully meets all Belgian laws as well as the Commission standards and requirements. Our accounting system is fully geared to ensure effective and efficient financial reporting and control of complex European projects.

In 2012 we were able to write off a large portion of the World Congress 2010 loss and we expect to write off the remaining loss in 2013. However, our level of reserves and the cash-flow are constant concerns. Reserves are far too small to support our association through possible future financial difficulties. Delays in payments of the European Commission often lead to cash-flow problems. I therefore call upon all members to pay their membership fees as early as possible each year.

I express my sincere thanks to all our members who paid their fees in 2012: 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





The European Association of Societies of Persons with Intellectual Disabilities and their Families

In 2013, Inclusion Europe moved its Secretariat to:

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The seven-year programme targets all stakeholders who can help shape the development of appropriate and effective employment and social legislation and policies across the EU-27, EFTA-EEA and EU candidate and pre-candidate countries.



For more information see: <u>http://ec.europa.eu/progress</u>

The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.