Annual Report 2011





Inclusion Europe

A LETTER FROM THE PRESIDENT







Maureen Piggot is the president of Inclusion Europe.

She talks about the work Inclusion Europe did in 2011.



Inclusion Europe worked to make sure everyone knows what people with intellectual disabilities need.

Inclusion Europe organised many important meetings and finished some big projects.

Maureen Piggot thanked to everyone who helped Inclusion Europe in 2011.

Dear members and friends of Inclusion Europe,

I have the great honour of sharing with you the outstanding achievements of Inclusion Europe in 2011.

As the United Nations Convention on the Rights of Persons with Disabilities entered into force at European level, we took the opportunity to make the voice of people with intellectual disabilities and their families even stronger.

In 2011, we celebrated two important gatherings of the intellectual disability movement. First, we took action to strengthen the role of families at our annual congress held in Cyprus. We were also very pleased with the results of the second European conference for self-advocates. More than 80 self-advocates from all over Europe provided great inspiration and energy for our work on rights and equality.

Furthermore, we continued to stir debate on the issues at the heart of full civil rights for citizens with intellectual disabilities, namely, the right to enjoy full legal capacity and the right to participate in political and public life. Our Recommendations for Accessible Elections in Europe were widely disseminated among politicians and decisionmakers.

Inclusion Europe also prepared the ground for better implementation of the rights of children with intellectual disabilities. The report produced within the project 'Children rights for all!' shone a light on the reality of this 'forgotten' group of children and challenged governments to take immediate action to enforce their rights.

The following pages provide an overview of our major endeavours and achievements. I would like to express Inclusion Europe's gratitude for the ongoing support of the European Commission as well as for the firm commitment of our members and supporters.

Mowen Kgg V.

Maureen Piggot President

UNLOCKING THE DOOR TO EQUAL RIGHTS





Legal capacity means that you can take important decisions in your life. For example, you can vote, get married or sign a contract.

But many people with intellectual disabilities do not enjoy the right to legal capacity.

In 2011, we worked to make sure everyone has legal capacity.



For example, we organised a meeting to tell politicians that everyone has the right to make important decisions in their lives.



We also organised a visit to Germany to see how people with intellectual disabilities take their own decisions with help of their support persons.

We also started a new project called Topside. It is about people with intellectual disabilities supporting their peers in taking decisions.



We did research to find out about the lives of children with intellectual disabilities in Europe.



The research showed that children with intellectual disabilities have less rights and chances than other children.

We came up with some ideas on how to make sure that children with intellectual disabilities have more rights.

Ensuring self-determination

Legal capacity is the key to the exercise of a whole range of fundamental human rights, including the right to vote, get married or to have a job. According to Article 12 of the *United Nations Convention on the Rights of Persons with Disabilities*, governments must ensure that all people with disabilities enjoy full legal capacity and provide them with adequate support to exercise this right. Reforms of national legislations to comply with Article 12 are thus of major importance for members of Inclusion Europe.

In November 2011, Inclusion Europe brought the issue to the European Parliament where it organised the first annual roundtable meeting on legal capacity and supported decision-making. In defining the roadmap towards equal recognition before the law, the following elements have been identified to prepare the soil for the much needed reforms of legal capacity legislation:

- Capacity-building to support the self-advocacy movement
- Mainstreaming the provisions of reasonable accommodation in all areas of legislation, not only in employment

- The establishment of safeguards such as trust and support networks
- Collaboration between support services and legal professionals, allowing for adequate assessment of the quality and extent of support for the person's needs

During the meeting, international exchange of good practice was deemed by many as the way forward. Inclusion Europe's **Working Group on Human Rights and Non-Discrimination** is aware of the need to bring this concept closer to people and offers a platform for discussion about how these models look. Relevant information and additional links are provided at www.e-Include.eu under the Legal Network News – Legal Capacity.

In September 2011, the working group organised a study visit to Hamburg for members of Inclusion Europe. The participants learned about the German model of supported decision-making laid down in the German legal assistance and representation law of 1992 (Betreuungsgesetz).

Having abolished the incapacitation procedure, the law allows the nomination of a legal supporter to provide assistance with legal issues but does not



restrict the individual's capacity to act independently. The participants took the opportunity to see the day-to-day implementation of the German model in practice, to understand the role of the different stakeholders and to learn about their satisfaction with the system.

Developing peer-support

The objective of the **project TOPSIDE** will also contribute to the discussions on the implementation of Article 12. The project was launched in November 2011 with the financial support from the Lifelong Learning Programme of the European Commission. It is geared to provide people with intellectual disabilities with the appropriate training needed to take their own decisions and become active citizens.

The project TOPSIDE aims to tackle this challenge by advancing the concept of peer training and support in Europe. It is undertaken in partnership with disability organisations in Finland (KVTL), Romania (Pentru Voi), Scotland (ENABLE), Catalonia (Dincat), the Czech Republic (SPMP) and the Netherlands (Perspectief). The project partnership will create and test a training curriculum for people with intellectual disabilities to train and support their peers. It will consist of various modules covering different areas of necessary expertise and experience.

The TOPSIDE project may offer new employment or volunteering opportunities for people with intellectual disabilities to reinforce their active citizenship through the recognition of their skills.

Making children's voices heard

After two years of extensive research, the European report on the implementation of the United Nations Convention on the Rights of the Child for children with intellectual disabilities was officially launched on 20 October 2011 in Brussels. This report examines the protection of the rights of children with intellectual disabilities in the area of education, health, abuse, participation, family support and community-based services.

Although a number of good practices in promoting the rights of these children have been recorded, the systematic approach is still missing. The lack of data on children with intellectual disabilities significantly impedes the real implementation and monitoring of their rights.

This European report together with individual national reports covering 22 EU member states is now available as a lobbying tool to ensure inclusive opportunities for children with intellectual disabilities. Detailed policy recommendations were developed to draw a roadmap towards better implementation of the rights of children with intellectual disabilities in Europe.

The reports were officially presented to the public at a final conference in presence of Jan Jařab, the Regional Representative of the UN High Commissioner for Human Rights, delegates from the Council of Europe, UNICEF and the EU Fundamental Rights Agency as well as disability and children's rights NGOs.

Inclusion Europe thus concluded the project 'Children's rights for all!' undertaken in partnership with Eurochild and the Charles University in Prague; with the financial support from the DAPHNE III Programme of the European Commission.

Each national report is available in both original version and English; the European report can be downloaded in 22 European languages at <u>www.childrights4all.eu</u>.

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ENHANCING PARTICIPATION





Inclusion Europe helps people with intellectual disabilities become active members of the community.

In 2011, we worked to make sure everyone has the right to vote.



We also worked to make it easier for people with intellectual disabilities to take part in elections.

In 2011, Inclusion Europe drew the attention of European decision-makers to the continuing exclusion of people with intellectual disabilities from political and public life.

In particular, two major challenges were tackled:

- Deprivation of political rights by discriminatory legislation
- Inaccessibility of elections

In May 2011, Inclusion Europe's General Assembly adopted a position paper on participation in political and public life as a basis for people with intellectual disabilities to live as equal citizens.

Universal suffrage

Throughout 2011, Inclusion Europe was a part of the NGO coalition lobbying for the recognition of the universal right to vote by the European Commission for Democracy through Law, the Council of Europe's advisory body better known as the 'Venice Commission'.

The Commission had been reluctant to revise its Interpretative Declaration of the Code of Good Practice in Electoral Matters on the Participation of People with Disabilities in Elections since it was published in October 2010. This first version allowed for the deprivation of the right to vote by an individual court judgment based on the grounds of a proven mental disability.

Finally, in December 2011, the Venice Commission adopted a text supporting universal suffrage as "a fundamental principle of the European Electoral Heritage. People with disabilities may not be discriminated against in this regard, in conformity with Article 29 of the Convention of the United Nations on the Rights of Persons with Disabilities and the case law of the European Court of Human Rights."

Legal reforms are necessary to make sure that legislation on legal capacity does not continue to deprive people with intellectual disabilities from exercising their right to vote. Furthermore, positive measures need to be taken to ensure that people with intellectual disabilities can participate in elections by ensuring that voting procedures, facilities and materials are appropriate, accessible and easy to understand and use. In order to guarantee the free expression of the will of persons with intellectual disabilities, where necessary at the request of the elector, it also means allowing assistance in voting by a person of their own choice.

Improving the accessibility of elections

On 30-31 May 2011, Inclusion Europe brought together politicians, representatives of national

electoral commissions and the relevant government bodies together with other European and international stakeholders to discuss ways to ensure effective participation of people with intellectual disabilities in elections.

In the presence of Jean-Marc Delizée, Secretary of State for Social Affairs of Belgium and Libor Rouček, Vice-President of the European Parliament, Inclusion Europe called upon the European Parliament and national electoral authorities to ensure that the whole electoral process, including information, procedures and facilities, is made more accessible for all citizens.

On this occasion, Inclusion Europe presented *Recommendations for Accessible Elections in Europe* covering five key areas:

- Legislation on legal capacity
- Accessible information
- Training
- Support for decision-making in voting
- Access to the voting process

The *Recommendations* were produced within the framework of the project 'Accommodating Diversity for Active Participation in European Elections' (ADAP)

and proved to be a key tool for Inclusion Europe's advocacy activities. Also important was the collection of *Good Practices for Accessible Elections in Europe* published within the framework of the project.

Through this work, Inclusion Europe has provided national and European politicians and electoral authorities with clear guidelines on how to ensure the equal and meaningful participation of persons with intellectual disabilities in the electoral process.

The project 'Accommodating Diversity for Active Participation in European Elections' was undertaken together with self-advocates from Enable Scotland, Nous Aussi France and SPMP Czech Republic, with the financial support from the Fundamental Rights and Citizenship Programme of the European Commission.

The Recommendations for Accessible Elections in Europe are available in 21 EU languages and include an accessible version. The collection of good practices and an easy to read guide on campaigning for accessible elections were published in Czech, English and French.

For more information, please, visit <u>www.voting-for-all.eu</u>.



ADVANCING COMMUNITY INCLUSION





In 2011, Inclusion Europe worked to make sure people with intellectual disabilities can live independently and be part of the community.



We work to make it easier for people with intellectual disabilities to live the way they want.

We started a project to make sure people with intellectual disabilities can learn new things all their lives.

Achieving community living in Europe

In 2011 Inclusion Europe continued to campaign for the right of people with intellectual disabilities to live independently and to be included in the community.

Inclusion Europe contributed to the **Global Campaign of Inclusion International to promote Article 19** of the UN Convention on the Rights of *Persons with Disabilities.* European self-advocates shared their personal experiences of how people with intellectual disabilities live and participate in the community in different countries of Europe. In addition, Inclusion Europe organised focus groups under the title 'Voices from Europe' where selfadvocates discussed their vision of living in the community, the barriers they encounter in everyday life and the support they need to overcome them.

As a member of the European Ad Hoc Expert Group on Transition from Institutional to Community-based Care, Inclusion Europe started cooperation with all relevant EU-networks to elaborate **common European guidelines on de-institutionalisation**. The purpose of this project is to reduce marginalisation and improve



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the inclusion and life chances of some of Europe's most vulnerable citizens by accelerating and improving the quality of de-institutionalisation.

Ensuring access to mainstream education

In November 2011, Inclusion Europe embarked upon the project 'Creating Pathways to Lifelong Learning for Adults with Intellectual Disabilities' (Pathways II) in order to enhance the accessibility of lifelong learning education in Europe.

The project builds on the legacy of the original Pathways project (2007-2009) which developed a set of tools for making the teaching process accessible to learners with intellectual disabilities. This included:

- European standards for making information easy to read and understand
- A training programme for lifelong learning staff
- A methodology on involving people with intellectual disabilities in the preparation and quality control of materials
- A checklist to assess the accessibility of written material

Pathways II makes these tools available to people with intellectual disabilities and to adult education staff in Croatia, the Czech Republic, Estonia, Hungary, Italy, Latvia, Slovenia, Slovakia and Spain through the involvement of Inclusion Europe's members in the project partnership. A series of training seminars will be held in each country. The project actively encourages education providers and decision-makers to improve the accessibility of lifelong learning programmes for people with intellectual disabilities.

More information about the project Pathways can be found at <u>www.life-long-learning.eu</u>.

Promoting inclusive and person-centred services

The final event for the European project "New Paths to Inclusion" was held as a part of the 2011

Europe in Action conference. The project operated with an innovative method of person-centred planning (PCP) as a means to facilitate an inclusive and self-determined life for people with intellectual disabilities inside their community. The concept of person-centred planning and practice was successfully transferred from the United Kingdom to Austria, Germany, the Czech Republic, Slovakia, Italy and Luxembourg. As part of the project, Inclusion Europe facilitated a survey on the use of person-centred services in Europe. The results together with the project experiences were compiled into the final publication available at <u>www.personcentredplanning.eu</u>.

Reaching out beyond Europe

Inclusion Europe launched an Inclusive Development Toolkit designed to mobilise local disability NGOs in Europe to get involved in development cooperation activities.

Organisations of people with intellectual disabilities in Europe have a unique potential to improve the situation of children and adults with intellectual disabilities in developing countries. The toolkit provides them with necessary knowledge of development cooperation issues, policies and contacts at national and European level to ensure greater support for people with intellectual disabilities and their families in the developing world.

The toolkit was developed within the framework of the project 'Full Inclusion in Development Aid for People with Intellectual Disabilities and their Families' undertaken in partnership with Lebenshilfe (Germany) and Mencap (United Kingdom), with the financial support from the European Commission's programme 'Non-State Actors and Local Authorities in Development'.

The toolkit is available at www.inclusive-development.eu.

STRENGTHENING THE MOVEMENT





Inclusion Europe makes people with intellectual disabilities, their families and organisations stronger.

In 2011, we organised 2 big meetings:

- In spring, we organised a big meeting for families.
- In autumn, we organised a big meeting for self-advocates.



We also organised some trainings for our members to learn new things.

We also improved our website. Information on the new website is easier to find.

Involving families

Families and their role as promoters of social inclusion were under the spotlight at **Europe in** Action 2011 – an annual conference of Inclusion Europe. The conference took place between 12th and 14th May 2011 in Larnaca, Cyprus under the title 'Family Action for the Inclusion of People with Intellectual Disabilities in Society'. The event brought together self-advocates, family members and disability professionals in order to identify the main challenges for families with a person with an intellectual disability and discuss them with national and European decision-makers.

At this event, Inclusion Europe highlighted the role of families as major supporters of inclusion and empowerment of children and adults with intellectual disabilities and called for their involvement in the implementation of the UN Convention on the Rights of Persons with Disabilities.

The conference was organised in cooperation with the 'Pancyprian Parents Association for People with

Mental Handicap' and the 'Committee for the Protection of the Rights of People with Mental Handicap in Cyprus'.

Strengthening the self-advocacy movement

Delivering under the motto 'Nothing about us without us', Inclusion Europe organised the 2nd conference of the European Platform of Self-Advocates under the title 'Hear our voices'.

The conference brought together more than 130 selfadvocates and supporters from all over Europe and beyond to talk about their lives, their rights, and the *United Nations Convention on the Rights of Persons with Disabilities.* Well aware of their rights, participants shared their experiences and discussed ways of breaking down the barriers faced by children and adults with intellectual disabilities in their everyday life.

The workshops were exclusively led by self-advocates and tackled a number of important issues. These included the right to live independently and be

included in the community, the right to get married and start a family as well as access to quality health care and employment. The involvement of people with intellectual disabilities in monitoring the implementation of legal instruments to safeguard their rights was discussed with representatives of the Council of Europe and the European Union Agency for Fundamental Rights.

A number of important messages addressed to families, organisations and governments have arisen from the conference.

"Know that we are here to stay! Believe in us! We must take risks and make our own choices. Listen! We have something to say. We are the experts!"

The event was organised in cooperation with Fenacerci, Cercipeniche and Inclusion International and supported by the European Commission and the National Institute for Rehabilitation of Portugal.

Supporting our members

In 2011, Inclusion Europe organised a number of capacity building seminars for its members.

In May, the annual seminar on the monitoring of the United Nations Convention on the Rights of Persons with Disabilities took place within the framework of the Europe in Action conference in Larnaca, Cyprus. A study visit to Hamburg, organised in September 2011, provided members of Inclusion Europe with first-hand experience of supported decision-making model in Germany.

Another successful event was the first annual skillsharing and capacity-building seminar for Information, Communication and Press Officers from Inclusion Europe's member societies. Held at the end of August in Brussels, the seminar provided participants with strategies and tips on effective use of popular Social Media platforms to support inclusion and participation of people with intellectual disabilities in society.

Communicating inclusion

Inclusion Europe is constantly seeking to improve its information service as a means of empowering people with intellectual disabilities and their families and promoting social inclusion across Europe.

In 2011, Inclusion Europe took an important step towards more inclusive, user-friendly and engaging communication by carrying out a major overhaul of its main website <u>www.inclusion-europe.org</u>.

The site offers a wealth of information and resources on intellectual disability in Europe, covering topics such as social inclusion, non-discrimination, legal capacity, inclusive education, independent living or accessibility. Its design and structure have been substantially simplified and the website now offers accessible content in 28 languages.

In addition, the website is constantly updated with news and articles from the e-journal <u>www.e-</u><u>Include.eu</u>. Visitors to the site can readily engage with Inclusion Europe through the most popular social networking platforms such as Facebook, Twitter, Flickr and YouTube.



EUROPEAN PLATFORM OF SELF-ADVOCATES



In 2011, EPSA continued to implement its work-plan for 2010-2012. We have continued to make sure people know more about our abilities.

We have published 4 numbers of 'Europe for Us!' to make self-advocacy more visible at European level.

The Steering Group members wrote letters to all EPSA members, explaining what they were doing in their countries and why it is important to be an EPSA member.

We have also organised our General Meeting in Cyprus, were we have presented our mid-term report.

Our main successes in 2011 were:

- The set-up of a Coalition for Community Living in Croatia
- The connection with several schools to present easy-to-read in France
- And the local involvement in decision-making bodies in Scotland

And, most of all, we organised our second EPSA Conference.

The Conference was in Peniche, Portugal,

and it was a big success.

More than 80 self-advocates from all over Europe got together to discuss about taking control and being heard.

Main messages from the conference to politicians and decision-makers were:

- Do not cut the funding for services.
- Make greater efforts to shut down institutions.
- We want self-advocates in politics!
- We want results, not only words!
- Make things in the community accessible.
- Do away with institutions that don't let us live independently.
- We have the same rights to work.

BOARD MEMBERS

WHO WORKS FOR INCLUSION EUROPE

responsible for managing the affairs of Inclusion Europe.



Maureen Piggot President United Kingdom



Helene Holand Vice-President Norway



Andrew Doyle Vice-President Scotland



Hannes Traxler Treasurer Austria



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

Jerry Buttimer Ireland



Jordi Costa Molina Spain



Senada Halilcevic Croatia



Françoise Kbayaa

France



Ingrid Körner Germany



Krisse Paaskynen Finland



Jyrki Pinomaa Finland



Denise Roza Russia



José Smits The Netherlands

THE SECRETARIAT

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

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OUR MEMBERS

- Albania: Help the Life Association
- Austria: Lebenshilfe Österreich / Lebenshilfe Wien
- Belgium: ANAHM/NVHVG
- Bosnia Herzegovina: Zivotna pomoc / SUMERO
- Bulgaria: BAPID / Karin Dom Foundation
- Croatia: Association for Self-Advocacy / Association for Promoting Inclusion / Croatian Association of Societies for Persons with Mental Retardation
- Cyprus: Pancyprian Parents Association for People with Mental Handicap
- Czech Republic: Inclusion Czech Republic / Sebeobhájci Praha / Rytmus
- Denmark: Landesforeningen LEV
- Estonia: 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: Panhellenic Federation of Parents and Guardians of Disabled People
- Hungary: EFOESZ / EFOESZ Self-Advocacy Group
- Iceland: National Federation for the Handicapped
- Ireland: Inclusion Ireland / Union on the Hill Self-Advocacy

- Israel: AKIM Israel
- Italy: ANFFAS
- Latvia: Rupju Berns / Rupju Berns Latvian Self-Advocacy Movement
- Lithuania: VILTIS
- Luxembourg: APEMH / Ligue HMC
- Malta: Movement in Favour of Rights for Persons with Disability / INSPIRE - The Foundation for Inclusion
- The Netherlands: Stichting VG Belang
- Norway: NFU Norwegian Association for Persons with Developmental Disabilities / NFU Self-Advocacy Group
- Poland: Polish Association for Persons with Mental Handicap
- Portugal: HUMANITAS / FENACERCI
- Romania: Federatia Incluziune
- Russia: Perspektiva
- Scotland: Enable Scotland / Enable ACE Committee
- Serbia: Serbian Association for Promoting Inclusion
- Slovakia: Association for Help to People with Mental Handicap
- Slovenia: Zveza Sožitje / Centre Dolfke Bostjancic Draga
- Spain: FEAPS / Dincat
- Sweden: FUB / Rikssektionen Klippan
- Switzerland: INSIEME
- United Kingdom: Mencap
- Europe: European Co-operation in Anthroposophical Curative Education and Social Therapy - ECCE / Down Syndrome Education International / Special Olympics Europe/Euroasia

FINANCIAL REPORT 2011

It is my pleasure to report that in the financial year 2011 Inclusion Europe was able to achieve a surplus in its operation. Furthermore, our External Auditor has again certified that our book-keeping 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.

The financial results of the World Congress 2010 in Berlin indicate that there is an operating loss which will create a financial burden on Inclusion Europe. For this reason, we have used some of the year's operating surplus to accrue needed reserves for this loss. The remaining amount of this deficit will be recognized in 2012. Due to possible individual effects of the financial crisis in 2011 we also had to write off a larger amount in unpaid membership fees. This can contribute to cash flow difficulties for Inclusion Europe so I call upon all members to pay their membership fees as early as possible each year.

Despite these financial challenges, we continued to implement ambitious projects in 2011 and, together with our partners, we achieved excellent outcomes.

I would like to express my sincere thanks to all our members who paid their fees in 2011. My thanks also go to other funders and to the European Commission for their support for the different activities at European level for people with intellectual disabilities and their families.



Hannes Traxler Treasurer

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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: http://ec.europa.eu/progress

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





Inclusion Europe

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

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