



Respect, Solidarity and Inclusion are the fundamental values shared by all members of our worldwide movement of and for people with intellectual disabilities and their families. In 2004, we reaffirmed our commitment to these essential values.

Respect for people with intellectual disabilities is based on knowledge and understanding of their situation. Respect leads to tolerance and acceptance of people with intellectual disabilities as valued equal citizens in society. Respect for their opinions and for the choices they make is the basis for self-advocacy and all other types of advocacy on their behalf. The development of the self-advocacy work therefore continued in 2004 in cooperation with the European Platform of Self-Advocates to better integrate people with intellectual disabilities into our daily work.

Solidarity between weaker and stronger people and organisations is the essence of the Inclusion movement. Solidarity within societies guarantees the necessary quality services for and protection of people with intellectual disabilities. The activities undertaken last year by Inclusion Europe and many of our members to develop the capacity of member societies in Central and Eastern Europe is a good example of this solidarity.

Inclusion in all aspects of society is the result of respect and solidarity. Inclusion is the basis for the exercising of Human Rights and for the fight against discrimination of people with intellectual disabilities and their families. The Board of Inclusion Europe therefore identified the promotion of quality services as an alternative to large residential institutions as one of the main objectives of our association for the year 2004 and beyond.

This Annual Report provides a short overview of our recent achievements. As a European organisation, we often do not have a direct impact on the lives of disabled people and therefore our success can only be measured through the difference Inclusion Europe makes to our member societies.

Inclusion Europe supports its members in their efforts to improve the lives of people with intellectual disabilities and their families. We deliver projects that help member organisations compare the situation in their countries and in developing better practice in their services at national, regional and local level. We also offer a platform where organisations can build partnerships. As a European NGO we also have to make sure that the voices of people with intellectual disabilities and their families are heard and respected in European and international organisations.

Building on our key successes in 2004, we will continue with our work in the years ahead. We will extend and expand our activities in the areas outlined in this Annual Report, notably in the areas of community-based living, education for all and self-advocacy.

Inclusion Europe is grateful to the many friends and advisors – we could never achieve our objectives without your support! I thank also the Board and the Secretariat of Inclusion Europe for their continuing hard work for people with intellectual disabilities and their families in Europe.

Françoise Jan
President of Inclusion Europe



Inclusion Europe and its members share the same values.

They respect the opinions and decisions of people with intellectual disabilities.

Inclusion Europe wants everybody to work together.

They want people with intellectual disabilities to be included in society.

We should always have people with intellectual disability in mind when we organise meetings and conferences.

We supported our members in the new member countries of the European Union.

We promoted quality services for people who do not want to live in large institutions.

In the following pages you will read more about our work.

EXCHANGE



Working is an important factor of inclusion
© Feaps, Spain

The exchange of knowledge and experience is one of the most important objectives for Inclusion Europe. Numerous examples have shown that important initiatives and developments at national level have been stimulated by exchanges between people and organisations from different countries.

Non-discrimination is a key topic for Inclusion Europe. By the end of 2003, the Member States of the European Union had to transpose the Employment Framework Directive into their national legislation, but were allowed three more years to transpose the provisions against disability discrimination. As employment is an important factor for social inclusion, Inclusion Europe dedicated much of its time in 2004 to the follow up of the transposition process and its impact on people with intellectual disabilities and their families. The project "**Fighting For Our Rights**", which involves disability and equality organisations in seven countries, and the Congress "**Europe in Action**", held in Dublin from 27 to 29 May 2004, were key activities in this perspective.

Following a decision of the Board, Inclusion Europe also concentrated many of its exchange activities around the topic of development of community-based residential services for people with intellectual disabilities. As recognized by a Supreme Court decision in the United States, institutionalisation segregates people from their community and can be considered a form of discrimination. This concerns many people with intellectual disabilities. Both our Annual Congress "**Europe in Action**", and the final conference of the European Research Initiative on

De-institutionalisation, "**Included in Society**", held in Brussels on 22nd & 23rd October 2004, were an opportunity to share our concern on the high number of people with intellectual disabilities still living in large residential institutions, who often have no other option than to stay in such settings for their entire lives. Furthermore, there have been numerous reports from some countries about unacceptable living conditions and intolerable violations of the human rights and dignity of residents in these institutions.

Fighting for non-discrimination, social inclusion and respect for human rights is not only the job of a few activists, it is a duty for all of us, parents, self-advocates, professionals and decision-makers. In Dublin, at the Congress "**Europe in Action 2004**", the 230 participants talked about what we can do to promote our agenda for a better European society - one that would include all its members as full citizens.

We agreed on three directions:

- More choices
- More friends
- More inclusion in the mainstream of life

Furthermore, the discussions focused on five key themes:

- Growing up in families
- Inclusive education
- Community living
- Real jobs / good daytimes
- Participation in democracy

Children in an institution in one of the new Member States



Annual Report 2004

Inclusion Europe

EXCHANGE

At the conference “**Included in Society**”, we discussed the results of a study co-financed by the European Commission on the current situation of large residential institutions in Europe. The study makes strong recommendations for the development of community-based residential services. Over 100 persons with disabilities, family members, professionals and policy-makers adopted a Resolution on equal opportunities for disabled people to live included in society. It states that the exclusion of disabled people in large residential institutions is a disgrace for European social policy and proposes several steps to remedy this situation and stresses the need for independent advocacy support especially for those living in these institutions. Halting the building of new large institutions for disabled people is one of the most important immediate objectives. The European Union should also promote community-based services, monitor their development and support subsequent European research. As a result of the project, a report was launched and several of the project partners decided to continue the work started in 2004 and to set up the European Coalition for Community Living.

Also a number of other issues were at the centre of our exchange work in 2004:

- The legislation regarding legal capacity, guardianship and other forms of legal assistance in decision-making in the project “**Justice, Rights and Inclusion**”.
- The enlargement of the European Union and its importance for people with intellectual disabilities, in the project “**Enlargement for All**”;
- The portrayal of people with intellectual disabilities in the media in the project “**Real Live Media**”;
- The participation of self-advocates in decision-making in the project “**Diversity in Dialogue**”;

More information about Inclusion Europe’s projects is available on our website. Most projects receive the financial support of the European Commission.



It is important to share information.

It helps to make things better.

Inclusion Europe helps people to share information.

Last year Inclusion Europe looked at ways to make laws work better for people with intellectual disabilities and their families.

We organised a European project, “**Fighting for our Rights**” and a conference, “**Europe in Action 2004**”.

We shared experiences on support services for people with intellectual disabilities who want to live in the community.

We organised a study to find out how

people live in large residential institutions.

The study is called “**Included in Society**”.

We organised a conference where people said governments should stop building new large institutions.

People living in large institutions should receive support and advice.

The European Union should promote the development of good support services in the local community.

Inclusion Europe worked on other European projects: “**Justice, Rights and Inclusion**”, “**Enlargement for All**”, “**Real Live Media**”, “**Diversity in Dialogue**”.

SUPPORT

"BAPID's participation in Inclusion Europe's Capacity Building Project helped our local structures to get actively involved in prioritizing their specific developmental needs as well as to strengthen their networking. As result of exchanged concerns, practical experiences and better contacts in teams, the networking between parent member NGOs was considerably improved. They also gained confidence in taking responsibility for active local advocacy for the rights of their disabled family members". *Aneta Ivanova, Executive director, BAPID.*

Another important principle for Inclusion Europe is that all members should benefit from our work. Therefore, we developed a number of activities to support our members directly and indirectly.

On 1 May 2004, ten new countries became members of the European Union. Romania and Bulgaria will follow in 2007.

In the framework for the development of civil society in those countries, Inclusion Europe undertook to strengthen the capacities of its member organisations to represent the needs and rights of people with intellectual disabilities and their families; to expand the scope of their activities and to enhance their national leadership. Furthermore, there is often a critical lack of information and training in disability. Providing training is therefore one of the most important activity areas for capacity building, information development and awareness raising.

In 2004, we therefore developed two important projects:

■ "Capacity Building through Adult Education and Training with national organisations in Central and Eastern Europe" was implemented in Bulgaria, the Czech Republic, Estonia and Romania. In this project we supported our member societies to develop training programmes so that they may become nationally recognised providers of continuing education in the disability area. This may contribute to awareness raising for professionals, parents and self-advocates, for the enhancement of quality of social services, as well as for better overall awareness on disability-related issues at national level. This project is supported by the Open Society Mental Health Initiative.

■ "More Rights for Persons with Intellectual Disability" was a project where we documented and analysed the human rights situation of persons with intellectual disability in Belarus, Lithuania, Latvia and Slovakia. Starting from the UN Standard Rules on Equalization of Opportunities for Persons with Disabilities, the project mobilised the national as well as the local branches of our member societies. On the basis of individual Country Reports, national strategies were developed for each country. These national plans are used to raise awareness for persons with intellectual disabilities at decision-making level. Furthermore, the project enables the partners to plan the needs of the national organisation and the local branches. For this project we received support from the Aktion Mensch Foundation in Germany.

In 2004, Inclusion Europe initiated or continued several European projects involving many of its member societies as well as organisations working outside Inclusion Europe membership either at national or European level (see previous section). Several of these projects contain elements

Meeting with parents and professionals in BAPID



Annual Report 2004

Inclusion Europe

SUPPORT

aimed at supporting the self-advocacy movement in Europe. The appointment of a new Self-Advocacy Officer has given a new impetus to Inclusion Europe's strategy towards the promotion of advocacy and self-advocacy.

We also took part in projects coordinated by some of our members, among them 'Real Live Media' coordinated by FENACERCI, 'Diversity in Dialogue' coordinated by LEV, and 'Sudmobil' coordinated by ATEMPO.

In the framework of our projects, we publish brochures and position papers. They are used to support member societies in lobbying their national or regional authorities. Some of our brochures are written in easy-to-read language and are especially appreciated by those members who otherwise do not have access to this kind of information. In 2004, Inclusion Europe published the following brochures:

- 'Discrimination hurts deep down inside!' (in 10 CEE languages)
- 'Included in Society - Results and Recommendations of the European Research Initiative on Community-Based Residential Alternatives for Disabled People' (in 22 European languages)
- 'Fighting for our Rights - Using Non-Discrimination Law to Protect People with Disabilities' (in 6 EU languages and summaries in all EU languages)
- 'The European Union against Social Exclusion' (in 21 languages)
- 'Human Rights for Persons with Intellectual Disability in Central and Eastern European countries: a comparative report'
- 'Election leaflets' (in 10 languages)
- 'The Enlargement of the European Union'
- 'Human Rights of Persons with Intellectual Disability, Country Report Latvia'
- 'The differences between Mental Illness and Intellectual Disability'

We also contributed to the development and the dissemination of training material made available by the projects 'Real Live Media' and 'Diversity in Dialogue'.

Information about European Union policies, structures and financing are regularly provided via Include and via the Weekly Information Letter (in English and French as well as in German - thanks to Lebenshilfe Austria). This information helps members of Inclusion Europe to understand how decisions taken at the European level can influence their work, how they can react accordingly and benefit from EU policy and funding opportunities.



Inclusion Europe wants to support its members.

Our work should help all our members.

Sometimes we support our members directly.

In 2004, we organised a project for our members in the new countries in the European Union.

This project helped them to get better organised.

We helped them to help their members.

We had another project with our members in four countries in Central and Eastern Europe.

We helped them to look at the Human Rights of people with intellectual disabilities in their country.

We collected and published information on subjects important for our members.

Some information is available in many languages and in easy-to-read.

We help our members to publish and share good information.

INFLUENCE

" Our work in **namhi** in influencing policy at both national and international level is supported by the pioneering work of Inclusion Europe. The Self-Advocacy movement in Ireland in particular in recent years has taken its lead from the work of Inclusion Europe. In 2004, we had the unique opportunity of bringing together all of the Irish candidates for the MEP Elections at the Europe in Action 2004 conference held in Dublin. This was a prime opportunity for people with an intellectual disability, their families and supporters to make their views and issues known to potential MEPs." *Deirdre Carroll, Director, namhi.*



Europe in Action 2004 Round table with candidates to the European elections

Inclusion Europe has a very important role in influencing European policy on the needs of people with intellectual disabilities, their families and their representative organisations. Therefore, Inclusion Europe is active in all policy areas relevant to our membership. A very important part of this work is to inform the European institutions about the needs and wishes of people with intellectual disabilities and their families.

As mentioned earlier, the **development of community-based residential** services is very important for Inclusion Europe, especially in the context of the enlargement of the European Union and the discussions at the United Nations about a new legally binding Convention on the promotion and protection of the rights of people with disabilities.

Within the context of the project "Included in Society" contacts were made with several Members of the European Parliament (MEP) in order to raise the issue of human rights in some large residential institutions and the

need to develop more quality community-based services. After these discussions, Liz Lynne, MEP from the United Kingdom, formulated two Parliamentary Questions to the European Commission. In his answer, Commissioner for Employment and Social Affairs, Vladimir Spidla, stated that the study "Included in Society" has produced valuable results in that it has confirmed that community-based services provide better quality of life for disabled people. As a consequence, the Commission has decided to take the matter further in exploring the financial implications of de-institutionalisation. The Commissioner announced also the intention of the Commission to launch a study to analyse how current financial resources can best be shifted and re-allocated to community-based services." This study should be available at the end of 2006. Inclusion Europe also launched an extremely successful press campaign at the occasion of the launch of the final report of the project.

In 2004, European citizens elected the new European Parliament. On this occasion, Inclusion Europe produced material on the **European Elections** to explain the main issues for the coming years, e.g. broader anti-discrimination legislation, the reform of the Structural Funds, and the mainstreaming of disability issues in EU policy. Information was made available on Inclusion Europe's website and an easy-to-read leaflet about the Elections and the European Parliament was printed in 10 languages thanks to the support of the European Commission and the European Socialist Group. A Round Table discussion with Irish candidates for the European Parliament was also organised at the occasion of

Annual Report 2004

Inclusion Europe

INFLUENCE

the Congress "Europe in Action 2004". After the Elections, Board members of Inclusion Europe met with new Members of the European Parliament and presented our position in relation to the work they will undertake during the new parliamentary period.

Inclusion Europe also attended and initiated **lobbying meetings**. At these meetings, Inclusion Europe presented its policies; the results of its projects; the brochures issued in the framework of its work as well as the position papers adopted by the Board to inform the discussion at EU and international level on issues that concern people with intellectual disabilities and their families. Some of the main

issues discussed last year at these meetings were: the impact of non-discrimination legislation on employment of people with intellectual disabilities; the need to maintain strong social inclusion and social protection policies to fight against social exclusion of disabled people; the importance of accessible information for social inclusion of people with intellectual disabilities; the lack of recognition of the fundamental rights of people with intellectual disabilities; and the need for full achievement of human rights, access to justice and legal capacity and the need to develop alternative services to large institutions. We also organised lobbying meetings with national decision-makers at the request of our members.



Many things that concern people with intellectual disabilities and their families are discussed at European level.

Inclusion Europe influences decisions made by European and international institutions.

We inform European institutions about the needs and wishes of people with intellectual disabilities and their families.

We organise meetings with people who make decisions.

We write letters and send information to them.

In 2004, we looked at two things: European legislation and better support services in the community.

We discuss social exclusion of people with intellectual disabilities.

We tell people that their Human Rights are not always respected.

We tell people that it is hard for people with intellectual disabilities to use the law.



THE EUROPEAN PLATFORM OF SELF-ADVOCATES

"I have always spoken for myself and I do not like other people speaking for me." "EPSA is important because it shows that we actually can take decisions. It's important because it's the place where I can get experience from other countries and take something back to my country". *Donald Stirling and Lars Olsson, EPSA Steering Group members.*



Self-advocacy is about people with intellectual disabilities speaking up for themselves and for others.

They want to take their own decisions as much as possible.

The **European Platform of Self-Advocates** (EPSA) comprises organisations of self-advocates.

In 2004, EPSA drafted a new work plan for the coming years.

In the work plan, there are 5 priorities:

- To help people to decide more by themselves.
- To tell people about the abilities of people with intellectual disability.
- To help groups of self-advocates at local level.
- To make meetings more accessible.
- To get more accessible information and websites.

A Steering Group of four self-advocates runs EPSA.

They were elected at the last general meeting of EPSA in Dublin in May 2004. Ulla Topi is the Chairperson, Lars Olsson, Donald Stirling and Alain Pasquier are the other members of the Steering Group.

EPSA is also part of Inclusion Europe and three of the Steering Group members are also Board members of Inclusion Europe. All self-advocacy organisations can become members of Inclusion Europe and join the EPSA. EPSA received support from Inclusion Europe to help run it.

In collaboration with the new Self-Advocacy Officer of Inclusion Europe, several important documents were finalised:

- A new leaflet about EPSA;
- Rules for accessible meetings in several languages;
- Rules for good support.

We will use these documents to promote accessibility of meetings and events.

We met already with important people from the European Commission and the European Disability Forum to tell them that they should make their meetings more accessible for people with intellectual disabilities, especially the meetings important for them.

The Steering Group of EPSA took part also in several projects of Inclusion Europe and its members.

Inclusion Europe knows that EPSA wants more accessible information.

Therefore we developed easy-to-read material in each of its projects.

We printed some brochures and newsletters (Europe for Us, Include).

We put information on our website and we made CD-ROMs.

All publications are available from our Secretariat or on the Inclusion Europe website.

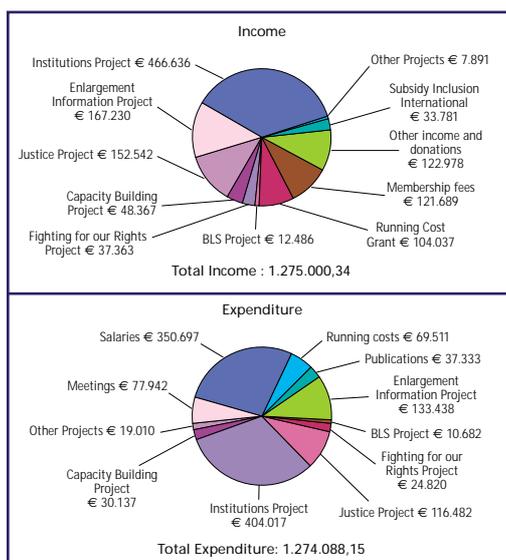
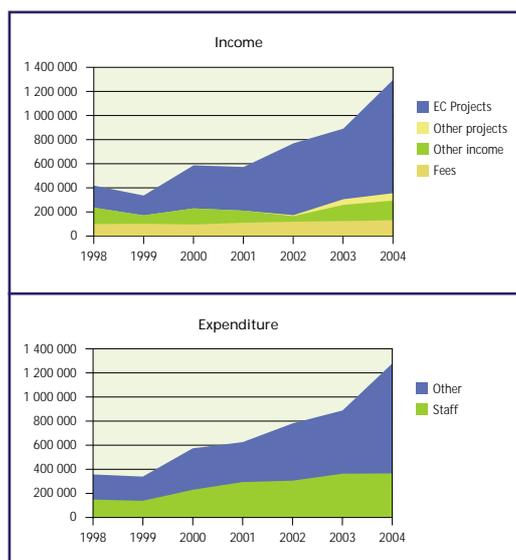
FINANCES

Also financially a strong and stable partner

It is my pleasure to report as Treasurer of Inclusion Europe that the financial situation of our association continues to improve. In 2004, we have for the first time in our history bypassed the threshold of 1 Million EUR of an annual turnover. On the following graphs you can see the development of income and expenditure of Inclusion Europe since 1998.

that the financial management and bookkeeping of Inclusion Europe is fully up to the standards of international accounting practice and the Commission regulations.

The following two graphics give you a more detailed breakdown of the sources of income and the areas of expenditure.



Our financial capacity has continuously increased while the level of membership fees stayed stable and the staff costs increased only moderately. This shows that our money is invested in concrete output, as the impressive number of reports, publications, meetings and conferences of Inclusion Europe shows. It is also encouraging that the income for projects financed by sources other than the European Commission increases. In 2004, our main sponsors outside the European Commission were Aktion Mensch from Germany and the Open Society Mental Health Initiative.

A concern, however, remains the low level of result for the year of only 912,19 EUR. This does not allow building up sufficient reserves for times of financial difficulties. The resulting problems in the cash flow have been resolved through a generous agreement with Inclusion International for which we are very grateful. Inclusion Europe will undertake new discussions with the European Commission in order to bring about an understanding of how reserves for the association could be build up without endangering the level of Commission subsidies. I thank all our members, sponsors and supporters for their continuous financial support.

The official auditors of the European Commission have furthermore confirmed, following a recent detailed audit of our accounts for 2001/2002

Jerry Buttimer, Treasurer



In 2004, Inclusion Europe had a budget of more than 1 million EUR.

This money comes from membership fees, the European Commission and other organisations that support Inclusion Europe.

We have many projects.

We spend a lot of money to print brochures and organise meetings and conferences.

Inclusion Europe does not make a profit.

This year the European Commission checked our accounts.

They said they were good.



Member Societies of Inclusion Europe are voluntary non-governmental organisations of persons with intellectual disability and/or their parents and friends operating at national, regional or local level. They are working exclusively in the interests of persons with intellectual disability. They are concerned with all phases of the lives and welfare of persons with intellectual disability, and are not limited in scope to a single or special service interest. Some members of Inclusion Europe are working at European level.

- **Austria** - Lebenshilfe Österreich www.lebenshilfe.at, Lebenshilfe Wien www.dielebenshilfe.at
- **Belgium** - ANAHM/NVHVG <http://users.skynet.be/ananm.nvhvg>
- **Bulgaria** - BAPID
- **Croatia** - Association for Promoting Inclusion
- **Cyprus** - Pancyprian Parents Assoc. for People with Mental Handicap
- **Czech Republic** - Inclusion Czech Republic, Sebeobhajci Praha
- **Denmark** - Landesforeningen LEV www.lev.dk, Udviklingshemmedes Landsforbund www.ulf-web.dk
- **Estonia** - Estonian Mentally Disabled People Support Organisation www.vaimukad.ee
- **Europe** - ECCE www.eccenet.com
- **Faroe Islands** - Javni www.javni.fo
- **Finland** - FDUV www.fduv.fi, Kehitysvammaisten Tukiliitto ry www.kvtl.fi/khvtl.htm, Me Itse ry, Steg för Steg ry
- **France** - Nous Aussi, UNAPEI www.unapei.org
- **Germany** - Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V www.lebenshilfe.de
- **Greece** - Panhellenic Federation of Parents and Guardians of Disabled People - www.posgamea.gr
- **Hungary** - EFOESZ www.efoesz.hu
- **Iceland** - National Federation for the Handicapped
- **Ireland** - namhi www.namhi.ie
- **Israel** - AKIM Israel www.akim.org.il
- **Italy** - ANFFAS www.anffas.it
- **Latvia** - Rupju Berns www.saule-rb.lv
- **Lithuania** - Lithuanian Welfare Society for Persons with Mental Disability www.viltis.lt
- **Luxembourg** - APEMH www.apemh.lu, Ligue HMC www.ligue-hmc.lu
- **Macedonia** - Republic Center for Helping Persons with Mental Handicap www.poraka.org.mk
- **Moldova** - Humanitas Association
- **Netherlands** - Federatie van Ouderverenigingen www.fvo.nl
- **Norway** - Norwegian Association for Persons with Developmental Disabilities www.nfunorge.org
- **Poland** - Polish Association for Persons with Mental Handicap www.free.ngo.pl/wyzwanie
- **Portugal** - HUMANITAS; FENACERCI www.fenacerci.pt, Association "A Casa de Betania"
- **Romania** - Romania Inclusiva
- **Russia** - Interregional Union of Life Help for Mentally Handicapped Persons
- **Slovakia** - Association for Help to People with Mental Handicap www.zpmpvsr.sk
- **Slovenia** - National Association for Intellectual Disabled People in Slovenia www.zveza-sozitie.si, Centre Dolfke Bostjancic
- **Spain** - FEAPS www.feaps.org
- **Sweden** - FUB www.fub.se, Rikssektionen Klippan
- **Switzerland** - INSIEME www.insieme.ch
- **United Kingdom** - Mencap www.mencap.org.uk, ENABLE www.enable.org.uk, ENABLE ACE Committee

Our allies

Inclusion Europe closely collaborates with and can count on the support of several organisations that defend similar objectives at European and international level:

Inclusion International:
www.inclusion-international.org

European Disability Forum:
www.edf-feph.org

European Social Platform:
www.socialplatform.org

Open Society Mental Health Initiative:
www.soros.org/initiatives/mhi

European Co-operation in Anthroposophical Curative Education and Social Therapy:
www.eccenet.com

Association for Research and Training on Integration in Europe, Autisme Europe, CECD Mira Sintra, Centre for Policy Studies at the Central European University, Center for Equal Opportunities and Opposition to Racism, Conseil Departemental de l'Aide Juridique, European Association of Service Providers for Persons with Disabilities, European Network of Independent Living, Geneva Initiative on Psychiatry, Hand in Hand Foundation, Mental Health Europe, Office of the Commissioner for Civil Rights Protection, University of Alicante, University of Göttingen, University of Kent – Tizard Centre; University of Mons-Hainaut.

Inclusion Europe receives the support of the European Commission for several of its initiatives. The information contained in this publication does not necessarily reflect the position or opinion of the European Commission.

www.inclusion-europe.org

21-22 October 2005

A Europe for All – International Conference on Poverty and Intellectual Disability
(Bucharest, Romania)

www.inclusion-europe.org/poverty



1-2 Decembre 2005

European Day of People with Disabilities
(Brussels, Belgium)



18-20 May 2006

Europe in Action 2006 – European Conference on continuing education
for adults with intellectual disabilities
(Brussels, Belgium)

www.EuropeInAction.org



4-10 November 2006

Inclusion International's 15th World Conference - Building an inclusive Future:
a challenge for globalisation
(Acapulco, Mexico)

www.inclusion-international.org



10-12 May 2007

Europe in Action 2007

Annual Report
2004



Inclusion Europe

Galleries de la Toison d'Or ■ Chaussée d'Ixelles 29, #393/32 ■ B-1050 Brussels
Tel: +32-2-502.28.15 ■ Fax: +32-2502.80.10
Email: secretariat@inclusion-europe.org ■ Internet: www.inclusion-europe.org

Re
S
Inclu