

# Users' Involvement in Social Services

Inspiring approaches to promote  
participation of persons with disabilities



IMPROVING SERVICES  
IMPROVING LIVES

European Association of Service Providers for Persons with Disabilities

# Contents

Executive summary.....2

Introduction .....3

Definition of Users Involvement .....4

Chapter 1.....5

    POLITICAL AND LEGAL BACKGROUND .....5

    WHAT DISABLED PEOPLES’ ORGANISATIONS SAY.....7

    EASPD’s STRATEGIC PLAN.....9

Chapter 2.....10

    WHAT EASPD CAN DO .....10

    WHAT UMBRELLA MEMBER ORGANISATIONS CAN DO.....11

    WHAT SINGLE AGENCY MEMBER ORGANISATIONS CAN DO.....11

    DATABANK.....12

Conclusions.....23

## Executive summary

EASPD's paper on involvement of users in social services starts with a comparative analysis of the most relevant legal instruments at the European and International level to certify the legal background of the subject, with a particular focus on the UN Convention on the Rights of Persons with Disabilities (CRPD) and the European Disability Strategy 2010-2020 (EDS). From this examination, it clearly emerges that participation of persons with disabilities within the cycle of service provision has become a key issue for the delivery of good social services.

In the framework of a continuous cooperation between EASPD and European Disabled People's Organisations (DPOs) a paragraph is dedicated to their opinion on the matter. The section describes the stance of Inclusion Europe, the European Disability Forum (EDF) and the European Network for Independent Living (ENIL) on the subject.

The paper then presents practical examples of how service providers for persons with disabilities can ensure users' involvement and participation and thus enable enjoyment of their rights. The chapter opens with an overview of actions that can be put in place by European networks, national umbrella organisations and single agency organisations providing services to persons with disabilities.

The second part of the chapter includes a databank of best practice examples. The section is composed of 21 examples on 7 main areas of involvement:

- ★ Advisory role in projects
- ★ Complaint procedures
- ★ Participation in governing bodies the organisation
- ★ Quality assurance of services
- ★ Research work
- ★ Staff recruitment
- ★ Training of staff

In the last section of the paper, we propose some conclusions underlining that it is necessary for service providers to recognise the role of disabled people and systematically promote their active participation in the development, provision and evaluation of the services they receive.

This paper is EASPD's first systematic contribution to research in this field and to promoting and disseminating good practices that are in place in our member organisations across Europe. It will be updated with new examples and contributions on a regular basis.

## Introduction

EASPD believes that the structure and quality of social services for persons with disabilities must be based on a continuous dialogue with the people using the services so that service provision reflects their expressed needs. In the past few years, European and International strategies have reflected a clear change in the approach to disability. Persons with disabilities have been recognised as citizens entitled to the same rights and equal opportunities as any other person. But these strategies need further emphasis on how mainstream and specialised services must adapt so that what they provide is tailor-made and shaped by the needs of each user.

EASPD, as a service providers' network, works for the full implementation of the United Nations Convention on the Rights of Persons with Disabilities. Service providers for

persons with disabilities are human rights enablers and they must fully involve users in services which support them. Whilst more can be done, many members of EASPD have developed good practices that successfully involve persons with disabilities in the provision of services. EASPD wants to build on these experiences and examples by providing our membership with tools to make a more inclusive approach in service provision a reality.

This paper concentrates on the involvement of people with disabilities in the management and development of services which support them. This is complementary to their involvement in society. EASPD believes that service provider organisations should lead by example. Encouraging mainstream society to welcome and promote participation can be done by leading by example.

# Definition of “Users’ Involvement”

## What do we mean by “Users’ Involvement”?

EASPD defines Users Involvement as the **systematic, ongoing and structural participation of service users in service development and provision, based on the principle that services must be built around people’s needs and preferences.**

This paper is about strategies to realise users’ involvement in an effective way. Its goal is to understand how to develop services with an active involvement of users in all phases, from needs assessment to service development, provision and evaluation.

The good practices presented in the paper are put in place by EASPD members, and have been collected via questionnaires and interviews.

## Chapter 1

*The principles of the present Convention shall be [...] the respect of dignity, individual autonomy including the freedom to make one’s own choices, the independence of the person and the full and effective participation and inclusion in society.*

United Nations Convention on the Rights of Persons with Disabilities, Art. 3

Participation of persons with disabilities in service provision has become a key issue in debates about disabled people and social services. People with disabilities continue to face numerous barriers that prevent them from full participation in all public and private activities. To address this situation, international and European legislators have created different tools to actively promote the inclusion of disabled persons in society.

This first chapter will look into the political outlook and legal basis for the promotion of users’ involvement at European and international level. We will refer to some of the most important Conventions, Strategies and Action Plans promoting the protection of disabled people’s rights:

- ★ The UN Convention on the Rights of Persons with Disabilities (CRPD)<sup>1</sup>;
- ★ The European Disability Strategy 2010-2020 (EDS)<sup>2</sup>, and its Initial Plan to Implement the Strategy<sup>3</sup> (Initial Plan);
- ★ The Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society (CoE Action Plan)<sup>4</sup>;
- ★ The European Voluntary Quality Framework for Social Services (EVQF)<sup>5</sup>.

## POLITICAL AND LEGAL BACKGROUND

The principle of empowerment and participation of service users is rooted in the **United Nations Convention on the Rights of Persons with Disabilities**, the first international treaty on the protection and promotion of the rights of persons with disabilities. It is also the first international human rights treaty to which the EU is a signatory. The CRPD, ratified by the EU in 2010, marked a radical shift in the definition and understanding of disability, moving from a medical perspective to a human-rights based approach. It is a human rights instrument with an explicit, social development dimension which requires States Parties to protect and safeguard the human rights and fundamental freedoms of persons with disabilities. It directly refers to the importance of their involvement in society<sup>6</sup> as a key element against discrimination and exclusion.

The CRPD finally confirms the change in perspective in the understanding of disability and disabled people that has slowly been developing. It asserts that persons with disabilities are **“subjects” with rights**, capable of claiming them and making decisions for themselves and their lives based on their free and informed consent as well as being

1 <http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

2 <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN:EN:PDF>

3 <http://eur-lex.europa.eu/LexUriServ/LexUriServ.do?uri=SEC:2010:1323:FIN:EN:PDF>

4 [http://www.coe.int/t/e/social\\_cohesion/soc-sp/Rec\\_2006\\_5%20Disability%20Action%20Plan.pdf](http://www.coe.int/t/e/social_cohesion/soc-sp/Rec_2006_5%20Disability%20Action%20Plan.pdf)

5 <http://ec.europa.eu/social/keyDocuments.jsp?type=46&policyArea=0&subCategory=0&country=0&year=0&advSearchKey=&mode=advancedSubmit&langId=en>  
SPC - A Voluntary European Quality Framework for Social Services (2010)

6 United Nations Convention on the Rights of Persons with Disabilities, Art 3, (b).

active members of society. It puts an end to the old perspective that defined persons with disabilities as “objects” of charity, medical treatment and social protection. Involving persons with disabilities in the development, provision and evaluation of services is therefore a necessary step to implement fully this change expressed so clearly in the Convention.

The **Council of Europe Action Plan** and the **European Disability Strategy** are international instruments at regional level, binding the members of the Council of Europe and of the European Union respectively. The CoE Action Plan was adopted in 2006 and its objective is to achieve the full participation of people with disabilities in society and ultimately mainstream disability throughout all policy areas in the Member States<sup>7</sup>. The EDS is in effect an implementation instrument of the CRPD at EU level. Its overall aim is to provide a framework for the European Institutions to empower people with disabilities, so that they can enjoy their rights by participating fully in society and in the EU economy and to remove the barriers that prevent this from happening. The EU is also responsible for ensuring the implementation of the CRPD in the areas in which it has competence – exerting a complementary action to that of its Member States.

Apart from the overarching principles inspiring these international pieces of legislation, two articles of the CRPD can be considered as the specific legal basis underpinning the principle of users' empowerment and participation:

- ★ The **right to equal recognition before the law (Art. 12 CRPD)**, which states that persons with disabilities have **legal capacity** on an equal basis with others in all aspects of life<sup>8</sup>;

- ★ The **right to live independently and be supported in the community (Art. 19 of the CRPD)**, which puts an obligation on both Member States and, indirectly, service provider organisations, to put into place adequate measures to develop community based services, *available on an equal basis to persons with disabilities and responsive to their needs*<sup>9</sup>.

Also the EDS and its Initial Plan place significant emphasis on independent living, through the support for the transition from institutional to community based care with measures such as staff training, adaptation of the social infrastructure and provision of support to families and informal carers. The CoE Action Plan dedicates a specific Action Line to “community living”, with explicit references made to users' involvement when talking about **users-driven, community based services and person-centred support structures**<sup>10</sup>.

Concerning EU legislation on service provision, the Social Protection Committee<sup>11</sup> adopted in 2010 the *European Voluntary Quality Framework for Social Services (EVQF)*, a set of methodological guidelines identifying quality principles that social services should fulfill and that can support public authorities in the definition, measurement and evaluation of service quality.

Section 3.2 of the EVQF is devoted to quality principles defining the relationships between service users and providers, developed around the principle of respect for users' rights, participation and empowerment.

**Respect for users' rights** means that service providers must respect the fundamental rights and freedoms of their users and their dignity, also in terms of equal opportunities, equal treatment, freedom of choice, self-determination, control of their own lives and respect for their private lives, as outlined in national, European and international human rights instruments. The quality criteria linked to this principle are:



- ★ Providing potential and actual users of social services with clear, accurate and accessible information, adapted to the specificities of each target group, notably about the type, availability, extent and limitations of the service provided. Information should also include independent evaluation and quality assessment reports;
- ★ Ensuring access for people with disabilities to means of information and communication adapted to their needs;
- ★ Implementing transparent, accessible and user-friendly advice and complaint procedures for users;
- ★ Providing workers and volunteers involved in service delivery with adequate training in rights-based, person-centred service provision of everyday care, in avoidance of discrimination and in awareness of the specificities of the groups of people they provide services to.

The principle of **participation and empowerment** states that service providers should encourage the active involvement of their users, and, when appropriate, of their families, trusted persons and informal carers in decisions concerning the planning, delivery and evaluation of services. Service provision should empower users to define their personal needs and should aim to strengthen or maintain their capacities while retaining as much control as possible over their own lives. Quality criteria linked to this principle are:

- ★ Ensuring involvement of the users and when appropriate, of their representatives, families, trusted persons or informal carers in the planning, development, delivery, monitoring and evaluation of the service, when necessary by providing adequate means, including supported decision-making and advocacy;
- ★ Engaging in dialogue with organisations representing users and involving them in the decision making process;
- ★ Establishing periodical reviews of users' satisfaction with the services provided.

The participation of service users in service provision is then not only required by international instruments, such as the CRPD, ratified by the majority of EU Member States, but is also a tool to assess the quality of services, as suggested by the EVQF.

## WHAT DISABLED PEOPLES' ORGANISATIONS SAY

As part of its overall strategy EASPD is in regular contact with key Disabled People's Organisations in Europe, among others with the European Disability Forum, (EDF), the European Network on Independent Living (ENIL) and Inclusion Europe, in order to influence European policy and implement best practice.

As part of this overall approach, we will continue to consult with them on the development of our position on user involvement.

The **European Disability Forum (EDF)** is an independent NGO representing the interests of people with disabilities in Europe and aiming at protecting them against all forms of discrimination. To reach this goal, EDF is keen to underline the relevance that involvement has at all levels, starting from the involvement of disabled people in the services that provide assistance to them.

A clear reference to the need for users' involvement can be found in a paper that EDF issued in response to the European Commission Communication “Modernising social protection for greater social justice and economic cohesion: taking forward the active inclusion of people furthest from the labour market”.

7 Cit. Council of Europe Action Plan to Promote the Rights and Full Participation of People with Disabilities in Society: Improving the Quality of Life of People with Disabilities in Europe 2006-2015. FUNDAMENTAL PRICIPLES, P. 5.

8 This right is also recognised in the CoE Action plan. Cit. CoE Action Plan, Art. 12

9 Cit. United Nations Convention on the Rights of Persons with Disabilities, Art 19 (c), p. 14

10 Cit. Council of Europe Action Plan to promote the rights and full participation of people with disabilities in society: improving the quality of life of people with disabilities in Europe 2006-2015, p.6.

11 The Social Protection Committee is a body created by the Treaty on the Functioning of the EU (TFEU) that serves as a vehicle for cooperative exchange between Member States and the European Commission in the framework of the Open Method of Co-ordination on social inclusion, health care and long-term care as well as pensions.





In this document, EDF stresses the importance of creating a framework allowing interaction between all actors involved in service provision:

*Services for people with disabilities are a **triangle composed by the user, the service provider and the public authorities**. This requires a special legal framework and measures to ensure a **good interaction between the various actors**. A European action in this field should acknowledge this fact<sup>12</sup>.*

The **European Network on Independent Living** (ENIL) is a Europe-wide network of persons with disabilities whose mission is to advocate and lobby for Independent Living values, principles and practices, namely for a barrier-free environment, provision of personal assistance support and adequate technical aids.

ENIL lobbies for the use of EU funds (namely the Structural Funds) for the development of community-based services (such as personal assistance), rather than the renovation or building of new residential institutions for people with disabilities. According to ENIL, deinstitutionalisation is a precondition for the realization of the right to live independently in the community, as set out in Article 19 of the UN Convention on the Rights of Persons with Disabilities. The European Union needs policies which promote independent living. Deinstitutionalisation and independent living are the basis of active citizenship and the full involvement of people with disabilities in society. As experts of their own needs, people with disabilities themselves should be able to choose

and control the support they receive. This includes being able to choose their assistants and to employ them, if necessary with support. It also includes being able to choose where and with whom they live.

During the 2007 conference on user involvement organised on ENIL's initiative by the European Coalition for Community Living (ECCL), John Evans, a member of ENIL's Advisory Group and a Board Member of the European Disability Forum (EDF), stressed the importance of user involvement in service provision. He said that, as users of services, people with disabilities must have a central place in the design, provision and evaluation of services. In relation to stakeholder involvement, it is necessary to recognise that views of the different stakeholders should not have the same weight – it is the view of the user of the service in question that should count the most<sup>13</sup>.

**Inclusion Europe** is an association of people with intellectual disabilities and their families. They fight for equal rights and full inclusion of people with intellectual disabilities and their families in all aspects of society.

One of the policy areas of work of Inclusion Europe is the right to live independently. The organisation promotes the development of person-centred, inclusive, community-based services for persons with intellectual disabilities and demands active involvement of users in their design, management, delivery and evaluation. In the document "Users Council in Services" Inclusion Europe outlines a practical strategy to implement users' involvement in social services:

*People with intellectual disabilities are full citizens of their countries. Depending on the level of their disabilities [...] in some areas of life they need professional support in the form of reliable support services that help to take difficult decisions or help to solve complex problems.*

*Inclusion Europe calls upon all providers of services for people with intellectual disabilities to ensure a democratic and independent representation of users in the management of their services and an effective control of users of the key aspects of service provision. The existence of such independent representation and control is an indispensable indicator of the service quality provided.*

*An effective way to ensure democratic representation and control by users is an elected body of user representatives in each service that is supported independently from the service providers' interests. This body is called [...] a "Users Council".*

Clearly each of the above DPOs, and their national and local counterparts, are vitally important partners for EASPD in its efforts to develop user involvement, and we will continue to work closely with them.

## EASPD's strategic plan

It is EASPD's ambition to contribute to the promotion, protection and guarantee of the full enjoyment of human rights and fundamental freedoms by people with disabilities and their social networks<sup>14</sup>.

As an umbrella association, we are aware of many good practices in Europe both from our members and others. The need for services is increasing while at the same time, because of the economic crisis, there is pressure to either reduce or provide standardised services based on depersonalised economies of scale. So it is all the more important to promote and **disseminate** these **good practices**.

EASPD has several remarks and suggestions on the EDS and its Action plan to address to the European Institutions about how to best implement them in the field of service users' involvement.

Some of the key actions we would suggest are:

- ★ **Make person centred planning** the key requirement for all service provision;
- ★ **Ensure support for the informal network** of disabled people (informal carers and families), which is equally important;
- ★ Guarantee special support for the **transition period** from institutional to community based care, e.g. through Personal Future Planning;
- ★ Facilitate the transition towards community-based support models;
- ★ **Involve in a structural way persons with disabilities and their support providers in the development of policy plans** about disability in general and on independent living in particular;

- ★ **Promote self-advocacy** by persons with disabilities;
- ★ **Ensure access to education and learning** for persons with disabilities on an equal basis with others. They are essential in enabling people with disabilities to become active citizens and contributors to the economy;
- ★ **Promote** the further development of "supported decision making" services and training.

Users' organisation are involved in EASPD events and consulted when coming to the draft of position and policy papers.

In the next chapter, some suggestions will be made on how users' involvement can be promoted by EASPD's Umbrella Member Organisations (UMOs) and Single Agency Member Organisations (SAMOs), and by EASPD via its Executive Committee, Board and staff.

12 EDF response to the European Commission communication: "Modernising social protection for greater social justice and economic cohesion: taking forward the active inclusion of people furthest away from the labour market", February 2008. <http://cms.horus.be/files/99909/MediaArchive/library/Active-Inclusion-%20EDFPosition-Feb2008.pdf>

13 Conference Report: Involving people with disabilities in the development, provision and evaluation of quality community-based services, 20 - 21 April 2007 Zagreb, Croatia. Organised by the European Coalition for Community Living and the Association for Promoting Inclusion: [http://www.community-living.info/documents/UESeminar\\_Report\\_June06.pdf](http://www.community-living.info/documents/UESeminar_Report_June06.pdf)

14 Cit. United Nation Convention on the Rights of Persons with Disabilities, Art 1 (c).

## Chapter 2

The chapter showcases good practice examples developed and put in place by EASPD members. The intention is to build a regularly updated databank providing examples in some key areas of service development and provision so that other service providers can follow them to promote users' involvement in their own organisations. The key areas range from individual decisions about individual lives through to the strategic management of the organisation. The initial areas explored below are, in alphabetical order:

- ★ Advisory role in projects
- ★ Complaint procedures
- ★ Participation in governing bodies of the organisation
- ★ Quality assurance of services
- ★ Research work
- ★ Staff recruitment
- ★ Training of staff

EASPD has 3 types of members: umbrella organisations (UMOs), single agencies (SAMOs) and observers. UMOs are federations of service providers for persons with disabilities at regional or national level working in at least one country member of the Council of Europe, while SAMOs are organisations providing direct services to people with disabilities in at least one country member of the Council of Europe.

All of these organisations can play relevant roles in promoting inclusion of persons with disabilities. UMOs and SAMOs have different scopes of action. Obligations regarding involvement of users may be different, though there are also many similarities. This is why EASPD will outline and promote different key actions according to the level of operation of the organisations.



### WHAT EASPD CAN DO:

#### Awareness Raising

EASPD is a network of organisations providing services for persons with disabilities across Europe and as such is in a unique position to raise awareness on the importance of users' involvement, collect good practice examples and make them available to its membership.

#### Policy Implementation

As a key player in policy making at European level, EASPD is committed to encourage a full and adequate implementation of the CRPD with the aim of promoting and reaching the full involvement of disabled persons in society and in the services that support them.

#### Partnership

In its advocacy work at European level, EASPD will continue to work side by side with Disabled People Organisations, by involving them in the events and projects we organise, and consulting with them when drafting our policy papers.

#### Accessibility

EASPD has committed to improve the accessibility of information it produces and makes available by producing accessible monthly Newsflashes and preparing a new website which will have enhanced accessibility criteria. EASPD also plans to increase the number of documents it makes available in Easy to Read.

### WHAT UMBRELLA MEMBER ORGANISATIONS CAN DO:

UMOs are networks of service providing organisations and as such can play a key role in ensuring that their members are aware of the importance of users' involvement and in providing tools to enact practices ensuring involvement in all phases of service provision.

Given this role, they are in a unique position to promote users involvement both within their organisation and among their members in a variety of ways:

- ★ By carrying out research work and needs assessments to understand the needs of member organisations, analyse awareness of users involvement and disseminate best practices;
- ★ By promoting the inclusion of persons with disabilities in the governing bodies of their organisations;
- ★ By structurally including persons with disabilities in trainings and events provided;
- ★ By implementing monitoring systems to evaluate the effective involvement of service users in their member organisations. Persons with disabilities can carry out these assessments.

### WHAT SINGLE AGENCY MEMBER ORGANISATIONS CAN DO:

Following the same steps, Single Agencies can carry out various types of activities to ensure users' involvement in service development, provision and evaluation:

- ★ SAMOs can involve persons with disabilities in the recruitment of staff (as part of the recruitment panel, or organising meetings with users before the interview), in staff training and in the strategic management and planning of the organisation;
- ★ Project groups can plan the involvement of persons with disabilities in an advisory role in all events, projects, and research activities;
- ★ Producing systematic accessible and 'Easy to Read' communication materials to ensure real access to information for persons with disabilities;
- ★ Promoting the active participation of persons with disabilities in the quality assurance of services and putting in place complaint procedures which are easily accessed by service users;
- ★ Including persons with disabilities and/or their family representatives in the board and the governing bodies of the organisation.

## DATABANK OF BEST PRACTICES

Below we describe some of the best practices that have been collected among our members. We collected 21 examples coming from 7 different organisations members of the EASPD network from 6 different European countries. This section of the paper will be updated on a regular basis.

### Examples have been collected in the following areas:

- ★ Advisory role in projects;
- ★ Complaints procedures;
- ★ Participation in governing bodies of the organisation;
- ★ Quality assurance of services;
- ★ Recruitment of staff;
- ★ Staff training;
- ★ Research work.

## Best Practices for Umbrella Organisations:

### PARTICIPATION IN THE GOVERNING BODIES OF THE ORGANISATION:

#### BEST PRACTICE EXAMPLE

#### Learning Disability Wales (UK)

Learning Disability Wales is a regional umbrella organisation which operates with the aim to create a Wales that values and includes every child and adult with a learning disability.

Learning Disability Wales' governing document explicitly requires the organisation to have one seat on the Management Committee for a person with a learning disability. We have recognised this person is isolated and in the last elections to the committee ensured that 3 individuals with a learning disability will be on the committee. Further steps have been taken to ensure that Committee members with learning disabilities can fully participate:



Meeting room

- ★ There is an item on our Committee agenda where we review how accessible the meeting has been;
- ★ Use of 'traffic light' cards given to every participant in the Committee meeting, which they can raise if they do not understand what is being said (an amber card) or want a pause (a red card);
- ★ Gradual development of Committee papers so that they are more accessible, and in some cases *easy read*;
- ★ Paying for Committee members who have a learning disability to have a supporter to assist them.

The Management Committee has approved a participation strategy that will seek to ensure that there is the maximum visibility and participation of people with a learning disability in the full range of our activities. This strategy will develop and evolve over time.

#### BEST PRACTICE EXAMPLE

#### National Federation of Voluntary Bodies (FEDVOL) (Ireland)

In Ireland, there's a National Service Users Self-Advocacy Forum. It's a national organisation where people come together to discuss issues important in their lives and how to self-advocate. The National Seasamh (Stand Up for Yourself) is a Parliament of service users. Seasamh is a forum for people with an intellectual disability, run by and for people who access disability services, with independent support, and active in the South East of Ireland. These two organisations have been supported by the Federation to be created.

### RESEARCH WORK:

#### BEST PRACTICE EXAMPLE

#### National Federation of Voluntary Bodies (FEDVOL) (Ireland) Inclusive research network

The Inclusive Research Network (IRN) is a joint project of the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability.

The purpose of the Inclusive Research Network is to provide education and training in inclusive research methodologies, disseminate the findings from inclusive research nationally and internationally, provide a forum for dialogue and discussion among and with people with intellectual disabilities about research issues and provide a platform for influencing national policy in intellectual disability in Ireland through the voice of people with intellectual disability and their supporters.

The network comprises persons with intellectual disabilities only, who are supported by service members of their organisations throughout the country. They come together to agree on issues that they would like to research (housing, leisure programmes, sexuality and relationships). To make sure that this is meaningful, the network is supported by academic researchers that give advice on methodology.



The Inclusive Research Network (IRN) is a joint project between the National Federation of Voluntary Bodies and the National Institute for Intellectual Disability. It was established in the framework of the work on quality done by the Federation for a few reasons:

- ★ There was no partnership work between people with intellectual disabilities, agencies and universities on research projects;
- ★ There were no chances for people with intellectual disabilities to be co-researchers on projects;
- ★ There was little or no involvement of people with intellectual disabilities in research done about them;
- ★ There was a lot of research that did not look at the lives of people with disabilities;
- ★ There were organisations doing the same type of research separately and not getting together to share information;
- ★ There were no chances for researchers to learn about doing inclusive research;
- ★ There was no support for staff at their organisations to work with people with intellectual disabilities doing research;

The IRN has a governing body: there is a chair and a secretary who takes minutes; they meet regularly (roughly every two months).

The findings are occasionally presented to the Board of the Federation. The research findings are accessible and easy to read. There is a [report](#)<sup>15</sup> available online issued in 2010.

Researchers join the IRN by expressing an interest through their services. The sending organisation supports people to participate to the meetings. The independence of the network is its added value.

The Network facilitated an exchange with a Finnish organisation that established a similar network. It is important that the research has an impact and its outcomes have an influence on the service provision.

<sup>15</sup> The Inclusive Research Network. A Participatory Action Research Project, available at [http://www.fedvol.ie/\\_fileupload/Research/Final%20Report%20Printed%20Copy.pdf](http://www.fedvol.ie/_fileupload/Research/Final%20Report%20Printed%20Copy.pdf)



## BEST PRACTICE EXAMPLE

## Learning Disability Wales (UK)

Learning Disabilities Wales provides an easy read consultancy service: they 'translate' documents for the Welsh Government and other agencies. Where possible, people with a learning disability are employed to check easy read documents.

LDW is about to publish a practical guide, entitled 'Clear and Easy' about writing easy read documents.

This work is carried out with the involvement of persons with intellectual disabilities and with the aim of making information accessible to them.

**STAFF RECRUITMENT:**

## BEST PRACTICE EXAMPLE

**National Federation  
of Voluntary Bodies  
(FEDVOL) (Ireland)**

Users' involvement in staff recruitment is in place in some of the members of the Federation. Persons with disabilities receive training, are supported and participate to the interview board. They participate as team members. The person who applies for the job is informed that a service user will be there during the interview.

The service user receives training which involves information on the job specification of the interviewed persons, and support to understand what questions to ask. It is also vital that the job applicants are informed in advance.

## QUALITY ASSURANCE OF SERVICES

## BEST PRACTICE EXAMPLE

## Learning Disability Wales (UK)

In partnership with organisations representing people with a learning disability, their parents and carers, we have made representation to the two bodies responsible for inspections and regulation, that they include these stakeholders in their inspection teams. The bodies are the Care and Social Services Inspectorate for Wales and the Healthcare Inspectorate, Wales.

## BEST PRACTICE EXAMPLE

## UNAPEI (France)

UNAPEI has designed a questionnaire on quality care provision (*questionnaire sur la bientraitance*) aimed at service users with intellectual disabilities. The aim of the questionnaire is to raise awareness among service users on quality of care, and to enable them to be actively involved in quality assurance evaluation. The questionnaire also supports professionals in their daily work.

.....

**TRAINING OF STAFF:**

## BEST PRACTICE EXAMPLE

## Learning Disability Wales (UK)

Learning Disability Wales actively involve people with learning disabilities in the training they provide. They do this by:



- ★ As a matter of principle, identifying an individual with a learning disability to co-chair any conference that they arrange, including the main Annual Conference;
- ★ Steadily increasing the proportion of the training courses offered that are led by a person with a learning disability.

## BEST PRACTICE EXAMPLE

## UNAPEI (France)

In France, there is a legal requirement, since 2002, to involve users within services. Unapei promotes users involvement through the creation of a "social life council" (*Conseil de la vie sociale*) in each service. Training is provided on a regular basis to staff on how to best implement these requirements.

## Best Practices for Single Agency Organisations:

## ADVISORY ROLE IN PROJECTS

## BEST PRACTICE EXAMPLE

### Innovia (Austria)

Innovia was one of the partners in the project "My Rights, My Voice", which aimed at training persons with disabilities to become trainers and deliver training to staff in 6 different countries. The content of the training was linked to the UN Convention on the Rights of Persons with Disabilities. Before the first training, the staff of Innovia contributed to the adaptation of the programme to meet the needs of persons with disabilities.

## BEST PRACTICE EXAMPLE

## Lebenshilfe Salzburg (Austria)

Service users participate actively in a number of projects run by Lebenshilfe Salzburg – for example:

INVOLVEMENT IN EUROPEAN PROJECTS:

**Quality of Life Measures:** A Leonardo da Vinci project on the development of assessment instruments for quality of life at the workplace. Service users were involved in the development of the instrument and in the pilot application which took place in 8 European countries.

**Learning without barriers – learning without frontiers:** EFRE/ EuRegio cross-border project (Austria/ Germany) that foresaw the organisation of inclusive workshops on Rights, Personal Future Planning, and Evaluation (user and peer approach): experts with and without learning disabilities trained staff and service users from various organisations in the 2 countries. At the beginning and at the end of the project, 2 half-day conferences on Rights were held, with international experts and an invited audience of authorities and political decision makers.

INVOLVEMENT IN NATIONAL PROJECTS:

**Accessibility evaluation group:** a group of persons with intellectual disabilities was formed to assess accessibility in Salzburg during the planning phase of the self-advocacy conference to give adequate information to future participants and to raise awareness in our city. They generated a checklist for each kind of test setting (e.g. hotels, restaurants/ bars, public transportation...) and evaluated the settings. Results were used for conference material. The group also held a workshop at the self-advocacy conference with practical evaluation experience. After that they were invited to present at several other conferences and events.

**Easy to Read group:** a group of persons with intellectual disabilities and an assistant in a Lebenshilfe workshop did training on how to generate “Easy to Read texts”. They mostly work on internal texts for Lebenshilfe, but sometimes their services are also requested from third parties (e.g. authorities).



## PARTICIPATION IN THE GOVERNING BODIES OF THE ORGANISATION

### BEST PRACTICE EXAMPLE Hand in Hand Foundation (Hungary)

Service users are not represented in the governing bodies of Hand in Hand, but they are involved in the strategic planning of the organisation. They contribute to the multiannual activities plan by providing feedback and inputs in the drafting stage.

Service users are asked to provide feedback on the services and to express their level of satisfaction. This is done through focus groups.

3 focus groups are organised, involving 7 service users in each. One focus group involves people with intellectual disabilities, the other ones people with physical/ sensorial disabilities.

There is a third focus group for parents of service users to capture their feedback, too.

The focus groups are moderated by independent, external facilitators, so that participants can feel free to speak and give feedback. The focus group for persons with intellectual disabilities is also supported by a staff member who can facilitate communication, but in any case the moderator is trained beforehand. Moderators are also explained in detail on how to formulate questions to make them understandable, etc.

Focus groups are rather easy to set up – the main thing is to think about involving service users in service planning and doing it systematically!

### BEST PRACTICE EXAMPLE

#### Lebenshilfe Salzburg (Austria)

Service users are not yet included as regular Board members in the Governing body of the organisation but service users – and specifically self-advocates – are invited to all important meetings including long-term strategy meetings.

Self-advocates are also involved to participate, as representatives of the organisation, in political processes at regional and national level. For example, they are part of the working groups for the development of the new law on disability services in the Federal Region Salzburg. The only official representative for all Lebenshilfe organisations in the National Committee supervising the National action plan for implementing the UN Convention is a self-advocate.

People with learning disabilities can run for one of the Vice President positions on the national organisation Lebenshilfe Austria. The elected Vice President with learning disabilities is a regular board member, but with a separate election process.

#### How can this be implemented?

- ★ Support self-advocates to enlarge their competences, provide personal assistance for advocacy issues, listen to their wishes and requests, trust them to represent the organisation in important official tasks/ functions;
- ★ Set up rules for board membership and elections that guarantee user involvement;
- ★ Raise awareness within the Board if part of the members are reluctant to accept board members with learning disabilities as equals;
- ★ Use easy language during meetings and for minutes providing real opportunities to participate and contribute.

## QUALITY ASSURANCE OF SERVICES

### BEST PRACTICE EXAMPLE Lebenshilfe Salzburg (Austria)

Important issues have been identified for managing quality of services towards inclusion and quality of life for the users: continuous quality improvement at all levels, quality management also at system level, customer focus, results orientation, and the use of adequate methodology producing valid and reliable results.

From a user's point of view quality of life is more significant than quality of services and the quality of life concept is increasingly being used in service planning and evaluation. The core domains of life are the same for people with and without disabilities. Quality of life comprises subjective and objective aspects. Both types of information are important. Objective aspects strongly relate to our role as citizens with equal rights reflecting objectively assessable aspects of lifestyle and indicating whether a subgroup is disadvantaged. Subjective aspects are central to designing person centred services as they are shaped by our expectations, wishes, experiences, personality and values. User involvement in instrument development and assessment contributes to higher validity and reliability of results. Working with peer interviewers is rewarding in terms of quality of results and empowerment.

**The approach of Lebenshilfe Salzburg adopts the quality of life concept as a central feature.** E-Qalin, a young quality management system specifically adapted to service provision for people with disabilities, serves as framework for quality improvement. It is based on the principles of self-assessment, customer and results orientation, and continuous quality improvement towards excellence and best practice.

Quality management was implemented in the organisation through an inclusive project for the development of the mission statement, the definition of a framework for strategic planning and action as well as organisational development processes in all major departments.

Customers are directly involved in quality development: the users' perspective is the central outcome measure. Services are evaluated by quality of life measures specifically adapted for the target group: e.g. Quality Of Life Measures (QOL).

How the system works: peer interviewers assess QOL of service users: Lebenshilfe Salzburg trains people with learning disabilities to become interviewers and interview their peers in the context of service evaluation (QOL and satisfaction with services). The results collected in this manner are more valid and reliable than with other interviewers. People undergo an in-house training (10 days) with curriculum developed by Lebenshilfe Salzburg (based on international best practice and exchange). They also work with Quality of Life instruments developed with the participation of people with intellectual disabilities (see EU-project QOL Measures).

**Benchmarking is also an important aspect:** Lebenshilfe Salzburg is looking for organisations using the same instruments to compare results and learn from each other. Unfortunately this is rarely possible as little information on good assessment instruments is available for service providers. Many different instruments are in use, often developed by and for the organisation itself, and most of them are not even published.



### How can this approach be implemented?

- ★ Adopt user and results orientation: the quality of life approach is currently considered most promising;
- ★ Use a modern Quality management system as framework for quality improvement;
- ★ Design an inclusive process to implement your approach. Support the different target groups to really adopt the values behind it. These approaches have to be "lived" to have an effect on users' lives!
- ★ Involve users directly: ask them about their QOL and their satisfaction. Subjective QOL is essential for person centred services!
- ★ Use adequate tools: our results are only as good as the instruments to assess them. A set of well developed and tested assessment instruments should be used. Knowledge on such instruments is not easily available for service providers. EASPD is working on providing systematic information on this issue for its members.
- ★ Work with peer interviewers: it further empowers people with disabilities and provides more valid and reliable results. Training for interviewers is often connected to specific tools. If you want to use your own tools, you usually have to develop and conduct training yourself.
- ★ Comparison and exchange with others is valuable: it helps to put your own results into context and to learn from each other. If the results of all providers in a region (who use the same instrument) are published (e.g. by the authorities), it increases transparency for users and their families and enables choice according to quality and personal preferences.

### BEST PRACTICE EXAMPLE

#### Hand in Hand Foundation (Hungary)

Hand in Hand offers different services/programmes, and each of them has its own protocol in place. The protocol outlines how to handle problematic situations. It also ensures that service users can voice their concerns and describes the procedures to follow.

The situation is similar in terms of quality assurance – each protocol defines how quality is implemented and evaluated for each of the programmes on offer. So there is no involvement of users at "systemic" level, but only at programme level.

In the employment programme, 3 service users are involved in the quality assurance: they have an interview on a monthly basis to provide feedback on the activities put in place. Employers are also involved in this continuous evaluation system.

Feedback is provided regularly through a variety of means: interviews, questionnaires, or via online feedback. The best methodology for each situation/ person is then chosen.

This practice can be implemented easily. The most important thing is to have a clear plan in place and to develop tools to involve service users and ensure they can be adequately involved in the continuous feedback process.

### RESEARCH WORK

#### BEST PRACTICE EXAMPLE

#### Lebenshilfe Salzburg (Austria) Accessible and Easy to Read communication:

Several years ago a group of service users and staff participated in a specialised training on how to produce texts in "easy language". The group works according to the core methodology of Capito: different groups of people with learning disabilities check on "understandability" and to the contribute to the optimisation of texts.

The Easy to Read group works mainly on internal Lebenshilfe documents, but sometimes local or regional authorities ask for their (paid) services. For very important and official documents, the organisation works with specialised providers to get a "certified translation".

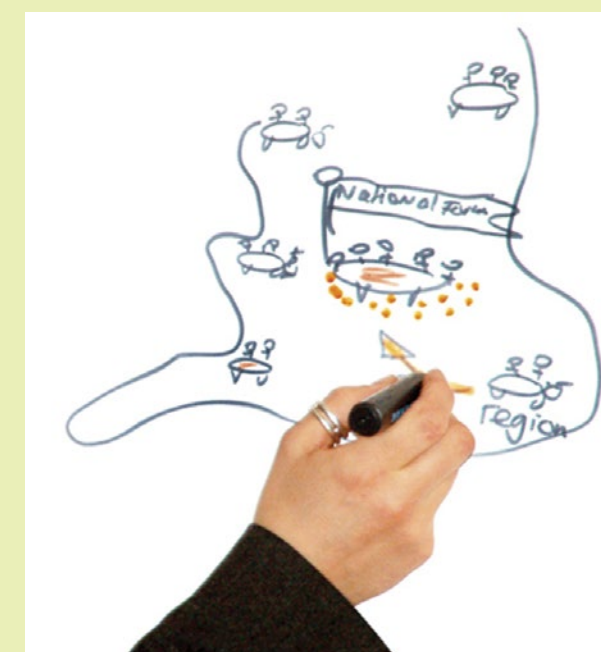
Lebenshilfe Salzburg has an accessible homepage in easy language, with a reading function as well.

Easy language and accessible information are available for a variety of activities: e.g. information for users in the local services; training and training materials for users – both inclusive and specialised; questionnaires and interviews for service users (e.g. Quality of life, satisfaction with services, satisfaction with training, ...); conferences and conference materials; information on and materials for user involvement in projects; index with detailed descriptions of all services and locations where services are provided.

### How can this be implemented?

- ★ By raising awareness within the organisation on the importance of accessible information beyond the small, local services. To include service users in important processes and decisions, most information must be provided in accessible format (including management issues ...);

- ★ By providing training for users and staff: some information is needed (or at least very helpful) in generating accessible information. You don't have to become an expert but should be able to take advantage of existing knowledge;
- ★ With creativity and courage: develop materials in-house (e.g. users and staff). It is fun, and it can be optimised every day. Don't be shy to take the initiative because you lack a specialised certificate. A lot can be done with the right attitude and understand that it is important!
- ★ Certified translation is recommended for official documents: there is a certain advantage in having a certified easy to read text if you print a large number of copies and distribute them widely.





BEST PRACTICE EXAMPLE

**Service Foundation for People with Intellectual Disability (KVPS) (Finland)**  
**Expert Group of KVPS Development team**

The Foundation supports people with an intellectual disability and others with special needs as well as their families. The Foundation wants to develop innovative practices in order to improve the quality of life for all those concerned.

One of the innovative practices developed by KVPS is the creation of the so called Expert Group, funded 3 years ago. The Expert Group evaluates documents and initiatives of KVPS, but it also contributes to staff training together with team members.

The Expert Group is composed of 8 people with an intellectual disability including people with profound disabilities. Some of them live independently, some in group homes; all of them need various kinds of support. Some of them have self-advocacy experience, but the majority doesn't. None of them had previous experience in working in such a group.

The group is facilitated by development team members.

Different methods and working tools are used to support participation and full involvement. Since the beginning it has been clear that traditional meeting techniques couldn't be used with such a group. Every document must be translated into "Easy to Read" and sensitivity is needed in handling certain topics. It is important to allow everyone to bring their ideas to the group, and to respect their opinions.

To improve motivation, it is important to work on the group's identity (producing business cards and their own email address). The motivation and the pride of being part of an expert group has had great impact on the personal life of the group members.

It is important that the group is permanent as it takes a long time to learn how to work together and it also allows membership identity. It is important to build up relationship based on trust and respect, that everyone feel listened and that their point of view and expertise are seen as valuable.

Resources are needed to make all materials accessible and to build up opportunities for expert group members to contribute to other activities such as lectures and presentations. Meetings have to take place frequently enough and concerning the duration, the best is having full day meetings with many breaks.

STAFF RECRUITMENT

BEST PRACTICE EXAMPLE

**Lebenshilfe Salzburg (Austria)**

Users are involved in the recruitment of frontline staff but not of staff recruitment in general. When a frontline staff member needs to be recruited the manager of the small local service and the head of the department lead job interviews with pre-selected candidates. The most interesting ones (one to three) are invited to come to the service for several hours (usually on different occasions) so that people with disabilities and team members have a chance to get to know them in an everyday/ work situation. After getting to know the candidates, team members and users give their impressions and preferences, and the manager of the local service takes the final decision building on this feedback and their own impressions.

**How can this be implemented?**

- ★organise opportunities for service users to meet candidates in "real life" situations and to deduct their preferences from the experiences they made;
- ★organise a meeting with service users to collect their impressions and preferences; observe people with high support needs (especially people that are non-verbal) in their reactions to the candidate/s;
- ★Present your decision to users and staff and share the reasons behind it; this provides another opportunity for influencing the hiring manager's decision.

BEST PRACTICE EXAMPLE

**Innovia (Austria)**

Innovia employs persons with disabilities: one third of their staff members have a disability. Employing disabled persons has a great impact on the culture of an organisation, things change on their own. Staff members with disabilities are involved in research work, sometimes focussing on accessibility and inclusion linked to their impairments. Staff training takes place and staff with a disability have a role in the planning and in the delivery of the training, as trainers.

The first project started by Innovia aimed at training 7 persons with learning disabilities to become experts in accessibility and equal opportunities. They had 43 modules ranging from orientation and mobility, IT (word, excel), team building, application for a job, or internship, organising accessible events, peer counselling, rights of persons with disabilities and the UNCRPD. After the 3<sup>rd</sup> year of training, 4 persons with learning disabilities were employed at Innovia and now work in another project aiming at training employees with (learning) disabilities to improve their qualifications as well as raising the awareness of companies and organisation in dealing with disability issues.

We had no certain methodology – we simply treated persons with (learning) disabilities like other staff members. Of course, more time, easy language and respect for other aspects of disabilities are needed.

Recommended methodology to follow to implement this practice: Start employing persons with (learning) disabilities in you organisation and it will develop by itself – for organisations the change of persons with disabilities from being a client to being a colleague has a real positive impact.

TRAINING OF STAFF

BEST PRACTICE EXAMPLE

**Lebenshilfe Salzburg (Austria)**

Service users are actively involved in delivering inclusive training: the organisation relies on people with intellectual disabilities' first-hand experience and expertise for staff training. The organisation has been working successfully with them in the initial training for new staff, introducing topics like self-advocacy, personal future planning, and communication. Feedback from new staff on these inputs is excellent. People with intellectual disabilities also give presentations and information for visitors (e.g. study visits from abroad, internships, politicians, authorities...).

On a related note, persons with intellectual disabilities receive increasing numbers of requests for inputs by external training centres and conference organisation committees. Staff members support service users in the preparation and/or delivery of workshops, presentations, etc. according to their needs and wishes. Additionally, Lebenshilfe Salzburg hosted a big self-advocacy conference last December, and implemented an inclusive steering group for planning and organisation. The decisions were taken by the self-advocates, they chose the issues to be addressed and the presenters. All workshops were either held by inclusive teams or by people with intellectual disabilities alone.





BEST PRACTICE EXAMPLE  
**Hand in Hand Foundation (Hungary)**

People with disabilities at Hand in Hand are heavily involved in training programmes. These are offered both to Hand in Hand staff, and to external organisations to whom Hand in Hand provides training.

The training has been accredited by the Hungarian authorities and is now offered by other providers as well. Its objective is to sensitise organisations/ workers to the needs of persons with disabilities and prepare them to be colleagues in a diverse environment.

The training session lasts for about 4 hours and is designed to get people perform various activities together. There are no “traditional” training sessions with an instructor providing information, rather, trainees and trainers are required to perform practical activities together. The objective is for trainees to understand the needs/ point of view of people with disabilities and realise they can work together as colleagues.

This training is offered both to external companies or organisations and to Hand in Hand’s staff. It is especially important for administrative/ management personnel who aren’t in direct contact, on a daily basis, with the service users, but all staff participates as it’s beneficial for all. It is run once a year, in conjunction with the arrival of new staff.

The training lasts half a day and it is run by a diverse group of people with disabilities – they all have different types of disabilities so that trainees can get exposure to different situations. Trainees have to carry out a variety of activities and exercises with the different disabled people, e.g.: cross a pre-determined path together with a wheelchair user; talk with a deaf person/ learn a bit of sign language to communicate with them; build a small house with a person with intellectual disabilities; and so on. These activities give an opportunity to people to work together and to talk, so they get to know each other and to understand what it means to have a disability. Usually, a parent of a disabled child participates too, to bring their specific perspective and expertise.

**What specific tool, if any, do you use to implement it?**

It is important to define a set training programme/ curriculum, so that diversity/ sensitisation training becomes part of the training offer of the organisation. It’s important to include people with different types of disabilities and a parent of a disabled child to ensure a well-rounded training.

# Conclusions

Involvement of people with disabilities as the users and legitimisers of services is crucial to ensure that services are shaped to meet their needs. This is a fundamental principle of the UN Convention on the Rights of Persons with Disabilities.

It is obvious that service providers should recognise the role of disabled people in the development and delivery of support systems. The full inclusion and involvement of persons with disabilities in a structural way in service provision cannot and shouldn’t be avoided. This is consistent with the CRPD’s principle of progressive realisation.

It is EASPD’s ambition to see comprehensive user participation in service provision become the norm, and this is why we have started working on this subject. Introducing practices and actions to promote users’ involvement at all stages of service provision doesn’t have to be difficult. As shown in the examples

presented in this paper, many procedures can be established easily. In this respect, services can learn from each other and innovative approaches can be promoted through cooperation and networking.

EASPD will continue working on this topic by sharing information, facilitating the exchange of best practices among our members and the regular updating and dissemination of our data bank as part of our review of our Strategic Plan.

The paper is addressed to EASPD members, and those with whom we work.

**If you want to contribute to the further development of this paper by providing examples of best practices on this topic, you can contact: [info@easpd.eu](mailto:info@easpd.eu).**

For further information on the best practices presented in this paper, please contact:

**Foundation for People with Intellectual Disability (KVPS, Finland)**

Kirsi Konola, Development Manager: [kirsi.konola@kvps.fi](mailto:kirsi.konola@kvps.fi)

**Hand in Hand Foundation (Hungary)**

Ákos Pordán, General Director: [pordan.akos@kezenfogva.hu](mailto:pordan.akos@kezenfogva.hu)

**Innovia (Austria)**

Johannes Ungar, Managing Director: [johannes.ungar@innovia.at](mailto:johannes.ungar@innovia.at)

**Learning Disability Wales (UK)**

[enquiries@learningdisabilitywales.org.uk](mailto:enquiries@learningdisabilitywales.org.uk)

**Lebenshilfe Salzburg (Austria)**

Karin Astegger, HR and Research & Development Manager: [Karin.astegger@lebenshilfe-salzburg.at](mailto:Karin.astegger@lebenshilfe-salzburg.at)

**National Federation of Voluntary Bodies (FEDVOL, Ireland)**

Brian O'Donnell, Chief Executive: [brian@fedvol.ie](mailto:brian@fedvol.ie)

**UNAPEI (France)**

[public@unapei.org](mailto:public@unapei.org)

## Acknowledgements

We would like to thank all members of EASPD for their comments, inputs and their answers to the survey they sent us that made this publication possible.

Special thanks for their precious collaboration go to Ákos Pordán, General Director of the Hand in Hand Foundation (HU); Brian O'Donnell, Chief Executive FEDVOL (Ireland); Céline Simonin, International Projects Officer UNAPEI (FR); Jim Crowe, Director of Learning Disability Wales (UK); Johannes Ungar, Managing Director INNOVIA (AT); Karin Astegger, responsible for the departments of Human resources and Research & Development at Lebenshilfe Salzburg (AT); Kirsi Konola, Development Manager KVPS (Finland).

Special thanks to Luk Zelderloo and Phil Madden for their supervision and their support.

## **EASPD – European Association of Service Providers for Persons with Disabilities**

Oudergemselaan / Avenue d'Auderghem 63, B-1040 Brussels

Tel: +32 2 282 46 10 | Fax: +32 2 230 72 33 | Website: [www.easpd.eu](http://www.easpd.eu)

EASPD Policy team:

Irene Bertana, Francesco La Rocca, Miriana Giraldi.

© EASPD 2012 - All rights reserved



EASPD acknowledges support from the PROGRESS programme of the European Commission, DG Employment, Social Affairs and Equal Opportunities. This document reflects only the view of the author and the Commission cannot be held responsible for any use which may be made of the information contained therein.