AGID

DEVELOPING TRAINING MODULES
FOR STAFF ON AGING AND DISABILITY ISSUES

Developing training modules for staff on Ageing and Disability Issues (AGID)

Final Report   Public Part

Project information

Project acronym:		AGID
Project title:		Developing training modules for staff on Ageing and Disability issues
Project number:		- 518175-LLP-1-2011-1--LU-LEONARDO-LMP
Sub-programme or KA:		Leonardo Da Vinci-LMP- Development of Innovation
Project website:		http://www.agid-project.eu/
Reporting period:	From	01.01.2012
	To	30.04.2014
Report version:		Final report
Date of preparation:		30.06.2014
Beneficiary organisation:		A.P.E.M.H
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This project has been funded with support from the European Commission.

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Executive Summary

The purpose of the AGID project was to develop a web-based learning platform for frontline staff and professionals on issues of ageing in persons with intellectual disability (ID). This project was aimed at frontline staff working with people with ID, and indirectly on people with intellectual disabilities and their families through consequent improvements in their quality of life, resulting from greater in-depth knowledge and training of support staff.

The AGID project identified the following core objectives:

- o to conduct a mapping of policy, needs and services for older people with ID based on needs analysis
- o to involve people with intellectual disabilities and their families in the formulation and development of the training
- o to involve professionals and frontline staff from a range of service agencies in the formulation and development of the training
- o to disseminate the training modules that were developed
- o to improve the quality of life of people with ID across Europe.

The AGID project consortium comprises university departments and services providers for people with ID from six EU countries who have been able to combine both theory and practice in contributing to the effective development of the project and to the achievement of appropriately focused outcomes. Each of the partners in the AGID project consortium has substantial experience and knowledge of the issues of ageing and intellectual disabilities thus bringing a strong European dimension of credibility and added value.

An innovative aspect of the AGID project has been the use of Appreciative Inquiry methodology (AI), allowing inclusion of all relevant stakeholders and enabling direct participation of people with ID within an EU project as well as their direct involvement in the design of the services with which they would like to be provided.

Since the AI approach is based on people's positive experiences and the creation of aspirations for useful actions in the future, the participation of people with ID is even more important in order to achieve inclusive outcomes. This process of data collection represented a very important step of the project since the outcomes of initial focus groups were used as the basis for the creation of the training modules for professionals supporting people with ID.

The training platform available in 5 languages (English, French, German, Italian and Flemish) has been composed in the following way:

1. **Module I "Ageing Process"**
2. **Module II "Person Centered Planning with older People with ID"**
3. **Module III "Communication and Social Networking of Ageing People with ID"**
4. **Module IV "Emotional Regulation and Support for Front line staff"**
5. **Module V "Pathological Ageing in Elderly people with ID"**
6. **Module VI "Taking Care: a Complex Professional Stance"**

The sustainability of the AGID projects' outcomes will be the continuation of the web based learning platform for a further five years beyond the project lifecycle in order to assure the

achievement of the individuated long term targets and goals.   The AGID project represents a clear investment in research and development in the area of aging and disability with the aim of achievement better quality of the services provided to the user as also involve the user within the development and evaluation of the services he is provided with.

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1.   Project Objectives

The core objective of the AGID project has been to improve the quality of life of people with intellectual disabilities who are faced with the challenges of ageing. This was to be achieved through improving the knowledge and competence of frontline staff and professionals in this field through the development of web-based training on the topic of ageing and intellectual disability.

A number of additional objectives were identified to be achieved at various stages of the project:

- To carry out a mapping of policy, needs and services for older people with ID based on an analysis of needs
- To involve people with ID and their families in the formulation and development of the training
- To involve professionals and frontline staff from a range of service agencies in the formulation and development of the training
- To develop a training module using the Delphi consensus method across partner countries
- To implement the training module through an innovative web-based format
- To evaluate the training module and its impact in providing personalised care for older people with ID
- To disseminate the training module, its methodology and impact in improving the quality of life of people with ID across European countries
- To reflect the UN-Convention on the Rights of Persons with Disabilities in all the steps of the project.

This project also addressed the following objectives of the Leonardo Da Vinci Programme:

- *Supporting improvements in quality and innovation in vocational education and training systems, institutions and practices.*
  The project set out to improve the quality of staff training in order to enable them to meet the needs of ageing people with disabilities in the most effective way. Training modules based on the outcomes of focus groups involving service users would lead to increased knowledge and skills that would enable staff to respond to the changes in users' lives.

- *Facilitating the development of innovative practices in the field of vocational education and training on a regional, national and EU level.*
  The project developed high quality and innovative staff training on specific issues related to ageing and disability. The results of each module delivered locally were shared across the whole partnership and then transferred to a European level.

- *Developing Vocational Skills taking into consideration the labour market needs – New Skills for New Jobs Platform*
  The project directly addresses Priority 3: "New skills for new jobs" since it focuses on the development of new skills for front-line staff. Participants in the AGID project

training modules learned new approaches; practices and competences that will help them face the new challenges in their profession.

The following LLP 'Horizontal' policy is fundamental to this work:

Promoting equality between men and women and contributing to combating all forms of discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation contributing to combating all forms of discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

2.   Project Approach

The innovative character of the AGID project is in the use of the Appreciative Inquiry (AI) methodology, through which people with ID and their families were involved from the beginning. AI was the methodology used for carrying out the focus groups in each partner country, the results of which form the foundation stone on which the topics and the modules have been developed.

AI is based on the principle of inclusion and incorporates the views of all the relevant stakeholders including service users, families and professionals. AI enables the exploration of ideas that people have about what is valuable in what they do and then tries to work out ways in which this can be built upon; the emphasis is on appreciating the activities and responses of people and thus differs from a more "problem-solving" approach.

The AGID consortium chose this methodology because:

- AI is a collaborative effort that involves multiple members or stakeholders conversing and working together

- AI is inclusive; it invites a widening circle of voices, representing all stakeholders within a system

- AI is generative; it fosters a dialogue that cultivates scenarios and theories that lead to greater cooperation and to higher performing work. Participants are drawn to work together toward a common vision.

AI is an approach that recognizes and values what works and is based on discovering the strengths associated with particular issues.

The phases of the AGID project follow the four main principles of Appreciate Inquiry:

- **Discovery:** *appreciating "the best of what is"*
- **Dream:** *imagining "what could be"*
- **Design:** *determining "what should be"*
- **Delivery:** *creating "what will be"*

The formation and process of the AGID has brought added value in particular areas:

- The membership of the consortium comprising both academic bodies and social services providers allows the topic to be considered from both a theoretical and a practical point of view, strengthening the likely effectiveness of the outcomes.

- The involvement of 6 European organizations has enabled a wide exchange of information and good practice from different cultural backgrounds.

- The starting point of the AGID project was the analysis of the currently challenging situation in Europe with regard to the ageing population and the project brings an

added value in providing possible solutions for the ageing issue of people with intellectual disabilities
- The inclusion of all stakeholders during all the project's phases, we believe, leads to better quality of services.

In order to implement efficient project management and ensure successful cooperation within the consortium several tools were designed and put in place. In particular, an internal evaluation was conducted among partners by means of a questionnaire to assess their level of satisfaction during the development of the project and to adjust the continuation of the project accordingly. The internal evaluation principally focussed on:

- The **project management aspects** (quality of the meetings, quality of the work organisation / realistic timetable, general evaluation of the project management)

- **Internal and external communication** (level of circulation of strategic information and feedback)

- **Quality of results** (coherence between original objectives and project results, integration of the project results in the practices / improvement of skills, relevance of results for end users, perspectives for creating new solutions and innovative concepts)

- **Quality of the partnership** (scientific quality or team expertise, complementarity of the partnership expertise matching, competences and tasks assigned to each partner).

Given the importance of this issue at the European level, the dissemination phase formed a core role in reaching the previously mentioned targets. The dissemination and valorisation strategy for the project consisted of:

Dissemination for awareness

It is important that people are aware of the work of the AGID project. This has been useful for those target audiences that do not require a detailed knowledge of the work but would find it helpful to be aware of the project activities and outcomes. We have targeted the general EU population and other organisations working in social services, raising awareness of the ageing of people with ID and their complex needs through the AGID website, AGID newsletters and AGID press release.
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Dissemination for understanding

Policy makers, frontline staff and health professionals were identified as essential targets. To reach them AGID has used the training modules, the training platform in e-format , specialty Congresses in the EU and worldwide on Intellectual Disability (MHID- Mental Health and Intellectual Disability), specialty journals on ID and publications (Publication "Necessary advancements in supporting people with disabilities"); Final Dissemination Conference AGID in Vienna, Dissemination of AGID Luxembourg (European Commission) and Dissemination of AGID in Bologna (social services department of Emilia Romagna Region). The AGID

outcomes and recommendations publication has also been used as an essential tool for disseminating awareness and understanding on ageing and intellectual Disability.

Dissemination for action

Action refers to a change of practice resulting from the adoption of products, materials or approaches offered by the AGID project. The target groups/audiences for action were those in a position to influence and "bring about change" within their organisations, those who need to be equipped with the relevant skills, knowledge and understanding in order to achieve real change. Health care professionals and policy makers are the primary target through the training modules, web-based learning platform and AGID brochure of achievements and recommendations.
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3. Project Outcomes & Results

All the project deliverables are accessible to the public through the AGID website http://www.agid-project.eu/ under the different work packages.

AGID outcomes delivered during the project cycle have met the identified objectives.

The main outcome has been the AGID training platform consisting of:

1. Module I   The Ageing Process
2. Module II   Person Cantered Planning with older People with ID
3. Module III   Social Networking and Communication of Ageing People with ID
4. Module IV   Emotional Regulation for Front- line staff
5. Module V   Pathological Ageing in Elderly people with ID
6. Module VI   Taking Care: A Complex Professional Stance

This has been used as a tool to disseminate the project results but also as a training resource and capacity building tool for any professional interested in issues of ageing and disability. The training platform will have considerable outreach and be accessible to a large number of staff working with people with ID, due to the wide spectrum (5 languages: English, French, German, Italian and Flemish) of languages in which the training material is available. The standardisation of training modules should lead to improvement in the quality of services and consequently in the quality of life of the service user.

The development of the content of the training platform achieved three main objectives:

- To make a link between contemporary research and the concrete experience of frontline staff.
- To develop a new and interactive training material that would focus on the needs of users and on the improvement of their quality of life
- To transfer this new training product to new target groups and in new geographical and cultural contexts.

This e-learning platform delivers easy-to-use, evidence-based material, with clear instructions for learners. Moreover, a range of technologies have been employed, including the use of interactive images, audio and video. Online quizzes and other interactive elements have been used to encourage self-assessment and a suitable e-portfolio utilised to monitor and manage a range of competencies and to provide an online learning space where users can reflect, collaborate and share experiences.

The impact of this is that it:

- Enables staff to access learning opportunities at times and places that best fit their lives.
- Permits access to knowledge and learning resources around the clock, from places that are most convenient for individuals and groups.
- Represents a great tool for capacity building of the staff, form whose knowledge depends the quality of life of the user

The AGID <u>Training Guide</u> has been designed to support people in their effort to acquire/convey knowledge and competences about working with ageing people with ID; this includes those who teach the module as well as front-line staff who use the online-version of the training. The primary objectives of the Training Guide are to:

- Support trainers to efficiently convey information to front-line staff
- Support front-line staff to plan their online training sessions
- Provide information on adult education

The guide provides information about the AGID program, the AGID modules, the use of the AGID training guide and key concepts. The guide also states the AGID general and specific objectives and for the training modules, the objectives of each module, learning outcomes and acquired competences expected. There is information on methods for successful training in adult education and specific advice on how to organise face-to-face training and what to consider when undertaking an online training

The impact of the <u>report of the focus groups by the whole consortium</u> represents an important operation of data collection in which outcomes of the focus groups could be compared between the different EU countries and cultures. The final report provides a mapping of needs of the service user, family members and of front life staff, from which the content of the training platform modules have been derived.

The <u>project website</u>, regularly updated with AGID's achievements, presents the partnership, the aims of the project (needs assessment, training modules, evaluations, power point presentation of the project, etc). The impact is the increased awareness of the issues and in-depth knowledge for the target groups such as: frontline staff and professionals in the disability sector, partners in local and international networks and European NGO's.

The AGID<u> publication</u> describes the project achievements at the very end of the project lifetime. It has been, and will be, used as the main dissemination tool within the disability field in Europe. The brochure is written in English and has been disseminated within partners networks and uploaded on the website, as well as being distributed in printed version to all ARFIE members (service providers to the disabled) and to many other stakeholders present at AGID dissemination events and activities. The expected impact is the one of reaching greater audience with the principle aim of dissemination for action, targeting primarily service providers and policy makers at national and EU level.

The impact of the <u>appreciative inquiry process of the focus groups</u> by contrast is the one of giving voice and visibility to service users' needs and the services with which they would like to be provided in order to improve their quality of life. This should not be underestimated since it allowed direct involvement of the people with ID and their families within the formulation of the training. Direct involvement of the person with ID within the formulation, development and evaluation of the training and in an EU project has been shown to be an effective tool for empowerment of the individual and an important step towards an effective implementation of the UN Convention on the Rights of Persons with Disabilities with particular regard to enjoyment of citizenship rights.

Service Users Involvement

The active participation of people with ID in the AGID project is in accordance with Articles 29 and 30 of the UN-CRPD which affirms the right of people with disabilities to actively participate in political and public life, including 'participation in non-governmental

organisations and associations' with the possibility of 'forming and joining organizations of persons with disabilities to represent persons with disabilities at international, national, regional and local levels'. Thus the inclusion and direct participation of people with disabilities within the creation, the development and the evaluation of this European project, represents a significant step forward in enabling greater enjoyment of these rights.

This involved:
Advisory role (main stakeholders, and core target) in the content development of the staff training

Ageing and elderly people with intellectual disability were involved from the beginning in focus groups to identify the individual nature of their social and health needs and thence the content development of the AGID Training platform. The Appreciative Inquiry methodology concentrated on the service users' experience and wishes and allowed the training content to reflect the person centred picture of users' needs and choice.

Quality assurance and evaluation of the training platform

The voice of the service user has been paramount within the evaluation of the content of the training modules through the anonymous Delphi process and direct feedback. Self-advocates with intellectual disabilities also played a prominent role in the final dissemination conferences which aimed to increase, accessibility through easy to read formats, 'buddies' and a graphic facilitator. Service users provided the main focus within 'round table' discussions on service quality and also the first feedback on the testing of the online training platform and its utility.

From the experience and findings of the AGID project it is clear that the participation of people with intellectual disabilities within the cycle of service provision is key to delivering quality services. Thus AGID strongly supports the adoption of co-production methodology within the service development and provision for the disabled.

Co-production defines people who use services as assets with skills rather than a demand or drain on resources, it is built on people's existing capabilities and breaks down the barriers between consumer (person with ID) and producer (service provider) by reciprocity and mutuality (people working together to achieve their shared interests).
Co-production involves:
- **Co-design (planning of services)**
- **Co-decision making in the allocation of resources**
- **Co-delivery of services** and **Co-evaluation of services with the person with ID**

4.   Partnerships

The AGID project brought together, at a European level, various partners involved in the care and support of disabled people. It included both social services providers and research institutes. The project benefitted from the expertise of two university bodies and the experience of social services providers from several European countries, ensuring that theory was brought together with the real life experiences and needs of users and stakeholders.

The Consortium had partners from 6 Countries: Austria, Belgium, France, Italy, Luxembourg and the United Kingdom. Each of the participants possess many years of experience in the field of disability and aging and also in education and training. Some of the members were previously involved in presenting the future challenges of ageing and disability and staff training related issues at the European Conference in Graz in 2006. Apart from the involvement of key experts, the consortium has a good balance of expertise from many points of view. The mixture of University bodies and social services providers organisations ensure that theory was brought together with the real life experiences and needs of users and stakeholders. The wide geographical coverage brings together both northern and southern countries (from the UK to Italy), covering a large part of European continent and thus bringing a wide European perspective.
The AGID consortium believes that a transnational approach, based on the experiences and knowledge of partners belonging to different cultural backgrounds and different ways of dealing with aging issues, is important in order to produce effective and durable results at European level. The members of the Consortium, based on their previous experiences on the Life Long Learning programme, have a wide international network of contacts (e.g. International Association for the Scientific Study of Intellectual Disability, IASSID) and have been able to capitalise on these networks to spread the outcomes of the AGID project.

Each Work Programme of the project was led and co-ordinated by one of the partners according to their specific experience and background.

- APEMH has 15 years of experience of supporting elderly and ageing people in residential care settings and day care centres and together with their training unit UFEP has worked on the content, organisation and setting up of the training modules to address the different needs of people with intellectual disabilities

- ZONNELIED brought its expertise in staff development and the methodology of Appreciative Inquiry (AI)

- University of Vienna and the De Montfort University have significant expertise in content training development and e-products.

- CADIAI has demonstrated experience in evaluation of capacity building tools and training platforms.

- ARFIE and Les Genêts d'Or instead, have great experience in strategic dissemination and exploitation of result. Together enjoy significant network of contents when research and service for Intellectual disabled are concerns, both at regional, national and EU level

5.   Plans for the Future

Two specific tools have been identified in the framework of the long-term dissemination strategy and exploitation of results: the website of the project and the e-learning platform. This choice aims to ensure the sustainability of the project and to promote valorization and better exploitation of its results and outcomes. In particular, the project's result will be mainly presented through the website and e-learning platform in order to increase the competences of the different communities of end-users as well as of the key stakeholders, at national and European level.
De Montfort University will be hosting the AGID training platform for a period of five years beyond the life of the project and it will be updated regularly to increase its validity in the light of changing policies and procedures. Moreover,   partners have committed to the scheduling of continuous training, located in each partner country and will promote the AGID training package on a national level.

It is expected that the outcomes of such accessible training, in different languages shall reinforce the EU and Members States' strategies on quality services for ageing and elderly people with ID. The standardisation of training modules for caregivers should lead to improvement in service quality and, as a result, a better quality of life for the individual with ID and their families.

The AGID project is a clear investment in research on aging and disability at the European level and in capacity building of the staff working with the user.

AGID supports and contributed to the following actions:

1. Inclusion and person-centered care for elderly and ageing people with intellectual disabilities; essential within service provision in order to meet the aspirations for a SOCIAL EUROPE
2. Capacity building of the workforce in delivering personalized care for older people with ID
3. Implementation of the UN-Convention on the Rights of Persons with Disabilities as   a first milestone into achieving equal rights and opportunities for all
4. Enabling access to better and safer healthcare for all citizens, so that everybody can benefit from high quality care, regardless of who they are and where they live.
5. Adoption of a human rights and person-centered approach when enabling ageing people with disabilities to live and participate in their community.
6. Development of formal education programs, training, and information provision on ageing and disability issues (knowledge, attitudes and values), including a human rights and citizenship perspective for staff and other carers.
7. Being proactive in anticipating and developing specific support for ageing people with disabilities who live with ageing family carers.

6.   Contribution to EU policies

The AGID project is grounded in the belief that high quality services should facilitate full participation, inclusion in society and full citizenship of people with disabilities, and as such the quality of social services for people with disabilities strongly depends on a continuous dialogue with the people who use them. The involvement of service users and all relevant stakeholders in the design, delivery and evaluation of services for the disabled are central to service quality thus AGID fully implemented the co-production in development and innovation in social services for the disabled, in order both to meet their evolving needs and to ensure the fulfilment of their rights.

In accordance with the European Disability Strategy 2010 – 2020, and the UN-CRPD, the AGID project promoted and achieved a significant contribution toward the rights of ageing people with ID through the following actions:

- **Participation**:[1] *"ensure that people with disabilities enjoy all benefits of EU citizenship; remove barriers to equal participation in public life and leisure activities; promote the provision of quality community-based services"*. AGID has enabled and encouraged the participation of people with ID within the decision making of the service provided to them, active involvement in EU projects, research and development of training package for the staff Art 29 e Art 30 UN CRPD).

- **Equality**: *"combat discrimination based on disability and promotes equal opportunities."* AGID aimed to address all forms of discrimination based on disability and age through a specific and innovative training program addressed to staff supporting people with disabilities who become older. As staff increase their skills and competences in dealing with disability and age it is envisaged that they will respond to users' needs in a more appropriate and person-centred way.

Article 8 of the UN CRPD is concerned with awareness-raising [2] and the AGID training platform raises awareness on ageism and its impact within services provided in the European Union. Targeting the staff working with people with disabilities and making them more aware of users' rights should have a positive impact on the effective implementation of the UN CRPD.

- **Social inclusion**: *"combat any type of social exclusion of people with disabilities"* Through raising awareness of the social needs of older people with ID, AGID intended to combat any type of social exclusion of the elderly disabled resulting from a lack of knowledge on their needs Within the training modules AGID has demonstrated that elderly people with ID are at risk of isolation in their social relationships (e.g. through ageing and death of their families and friends) and networks; this has also to be considered within the services provided to them .

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[1] http://ec.europa.eu/justice/discrimination/disabilities/disability-strategy/index_en.htm

[2] http://www.un.org/disabilities/convention/conventionfull.shtml

- **Health**: *promote equal access to quality health services of ageing people with ID*
  In line with Art 25 of the UN CRPD the training of carers and professionals developed by AGID on the general and specific issues of health and wellbeing in people with ID as they age should enable the provision of *'care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care[3];*

Nonetheless AGID innovative training platform is a clear contribution to EU VAT system as also the EU platform for New Skills for new jobs.

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[3] http://www.un.org/disabilities/convention/conventionfull.shtml