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

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Developing training modules for staff on Ageing and Disability issues

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Executive Summary

The AGID project is about developing a web-based learning platform for frontline staff and professionals on ageing and intellectual disability issues. This project will have a direct impact on frontline staff working with people with ID, and indirectly on people with intellectual disabilities and their families since the quality of life of the users' will be improved through greater in-depth knowledge and training of support staff.

The AGID project identified the following core objectives: to conduct a mapping of policy, needs and services for older people with ID based on needs analysis; involve people with intellectual disabilities and their families in the formulation and development of the training; involve professionals and frontline staff from a range of service agencies in the formulation and development of the training; disseminate the training modules that are developed and, most importantly, to improve the quality of life of people with ID across Europe.

One of the key aspects of the AGID project is the strong European added value and credibility due to the quality of the partners present in the consortium each of which has substantial experience and knowledge of the issues of ageing and intellectual disabilities. The consortium comprises university departments and services providers for people with ID from different 6 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.

It is worth underlining the innovative aspect of the AGID project- the Appreciative Inquiry methodology (AI) since it permits inclusion of all the concerned stakeholders and guarantees 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.

Within an approach like AI, that is based on good experiences and is the creation of expectations for useful actions in the future, the participation of people with ID is even more important to achieve inclusive outcomes. This process of data collection represents a very important step of the project since the outcomes of the Focus Groups are used as the basis for the creation of the training modules for professionals supporting people with ID.

Analysis of the content and conclusions of the Focus Groups revealed three main priorities:

- Autonomy and self-determination in the way of life (irrespective of age)
- The material means to provide at least the minimum comforts for a life with dignity
- The need for social relationships

Six topics appeared within the focus groups as being of essential relevance for improving the quality of life of older people with ID:

- **Emotional regulation and support for staff members working with older People with ID**
- **Person Centered Planning with older People with ID**
- **Communication and social networking of Ageing People with ID**
- **Taking Care: a complex professional stance**
- **Ageing Process**
- **Pathological Ageing in Elderly people with ID**

In addition to the modules, a number of tools have been prepared for the valorisation and dissemination of the results achieved so far: the AGID website, AGID newsletter, AGID press

in newsletters, conferences etc. The aim is to reach as wider audience as possible in order to raise awareness of these issues and to provide sources of information for further action.

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.

It is intended also that the long-term impact of the AGID project will be through the establishment of a strategy for lobbying and advocacy that will be targeted both on national policies and strategies for health and on disability (e.g. The National Strategy for Disability, as well as the National Action Plan related to the UN-Convention of the Rights of People with Disabilities).The AGID project represents a clear investment in research and development in the area of aging and disability at the European level and in the promotion of this knowledge in each country.

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1. Project Objectives

The core objective of the AGID project is to improve the quality of life of people with Intellectual Disabilities faced with the problems of ageing. The project intends to reach this goal by increasing the knowledge and the competence of frontline staff and professionals in this field through the development of web-based training on the topic of ageing and intellectual disability. The quality of life of elderly people with Intellectual disabilities and their families will be improved through increased knowledge of support staff working with the service-users.

AGID has identified additional objectives 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 the 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 will also address 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 aims 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 will impart increased knowledge and skills to 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 regional, national and EU level.*
The project aims to develop quality and innovative staff training on specific issues related to aging and disability. The results of each module delivered locally will be shared with 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 the 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 will learn new approaches; practices and competences that will help them face the new challenges in their profession.

In keeping with the European Disability strategy 2010 – 2020, the AGID project intends to “Raise disability awareness and specific knowledge among health professionals, considering the specific needs of female and male patients”.

This project also wants to demonstrate that the active involvement of the target groups (people with ID, their families and the professionals), during all steps of the projects, will bring them additional benefits. It was the participation of all the stakeholders in the Focus Groups (the basis for the creation of the training modules for professionals) that led to the three main priorities for users’ needs: autonomy and self-determination in the way of life, material means for at least the minimum comforts for a life with dignity and the need for social relationships.

2. Project Approach

The innovative character of the AGID project lies within the use of the Appreciative Inquiry (AI) methodology, where people with ID and their families were involved from the start in all the different phases of this project. AI has been the base for carrying out the focus groups in each partner country and the results of the focus groups are the foundation stone on which the topic 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 stakeholder 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. AI reverses our common point of view, from considering what is wrong to focusing on what actually works; it evaluates the previous experience of participants and assesses positive outcomes.

Deficits or negative outcomes are not ignored but the primary emphasis is on the drivers that can lead to attainment of a future vision. This requires us to find the best questions and routes of inquiry that can lead to new possibilities, inspirations and solutions.

A key role in this approach is that of a moderator that must be trained and familiar with the AI methodology and who will be able to work efficiently with participants who bring many years of experience in this area.

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

- **Discovery:** *appreciate “the best of what is”*
- **Dream:** *imagine “what could be”*
- **Design:** *determine “what should be”*
- **Delivery:** *create “what will be”*

ZONNELIED provided specialist knowledge of AI, and was responsible for training frontline staff from each partner in this methodology (WP II)

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 exchange has enabled a wide exchange of information and good practices
- 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 will, we believe, lead to more effective outcomes.

In order to implement efficient project management and ensure successful cooperation within the consortium several tools have been designed and put in place. In particular, as planned in the Project application, an internal evaluation has been 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 focusses 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 has a core role in reaching the previously mentioned targets. The dissemination and valorisation strategy for the project therefore consists of:

Dissemination for awareness

It is important that people are aware of the work of the AGID project. This may be 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. The main tools will be flyers, poster and the website.

Dissemination for understanding

There will be a number of groups/audiences that we will need to target directly with our dissemination such as policy makers, frontline staff and health professionals. A web platform will be created, which will continue for five years beyond the end of the project. There will also be a brochure of the AGID achievements and recommendations.

Dissemination for action

Action refers to a change of practice resulting from the adoption of products, materials or approaches offered by the AGID project. These target groups/audiences will be those that are in a position to influence and "bring about change" within their

organisations; those who will need to be equipped with the right skills, knowledge and understanding of our work in order to achieve real change.

In this case the delivery of training models will be promoted in each country to target service providers, support staff and policy makers.

It is important to consider the nature of the targets within a dissemination strategy. In the case of the AGID project, the targets will be local, regional, national and EU policy makers, front-line staff and health professional, as well as institutions and organisations working with disabilities and ageing issues.

At the EU level, dissemination activities will address: European Disability Forum; Social Platform; ARFIE members; IASSID; COFACE members; FRA Fundamental Rights Agency (Vienna); DG health and consumers.

At national and local level, AGID results will be publicised to: local news publications; local policy makers; Ministries of Health and Family matters; other organisations and Institutions working on disability and aging issues; seminars and conferences concerning health issues; publications in journals.

In addition, several tools will be used in order to reach the different targets: newsletters; briefings; conferences; reports; workshops; one-to-one; websites; media.

3. Project Outcomes & Results

The AGID project has so far achieved the following:

Meetings reports and minutes have been continuously delivered in order to set out the roles and duties of each partner during the project. During these meetings it has been decided who does what within each WP in line with what was laid out in the project application.

An **internal evaluation** has been conducted through a questionnaire among the partners of the consortium, in order to measure their satisfaction and their evaluation of the running of the project. (see above).

An external evaluation providing an independent monitoring of:

1. The impact of the training modules in the 6 countries. (A further evaluation will take place at the end of the project of the whole e-learning platform)
2. Evaluation of the project products (newsletter, website, training modules)
3. On-going support of the evaluation process within the project development (short term and long term evaluation)
4. General assessment of the project objectives, progress and outcomes (whether the aims have been met to timescale and anticipated quality) proposals and recommendations.

The organization of two days of training on the Appreciative Inquiry methodology

This also involved the distribution to the partners of an Appreciative Inquiry handbook with information on how to use the methodology during the conduction of focus groups and how to adjust this to the needs of the different stakeholders (users, family and staff) and to address the questions concerning quality of life of people with ID.

Progress report of the focus groups run by each partner.

Each report describes how the focus groups were composed, the questionnaires submitted to the stakeholders and adapted to their needs. The report records their stories and dreams, as well as a common dream. A first evaluation of the needs and expectations of the participants has been made at this stage and the common dream transformed into actionable items which have formed the basis for the training modules. **The objective of these products as described in the project application is both to conduct a mapping of policy, needs and services for elderly people with based on the needs analyses and to reflect the UN CRPD (art 29 and Art 30 participation and self-determination) .**

Summary report of the focus groups by whole consortium.

The leader of this WP has coordinated the different results from each focus group report. The analysis led to the elucidation of three main principles: Self-determination and autonomy in the way of life (irrespective of age); The material means to provide at least the minimum comforts for a life with dignity and the need for social relationships.

The production of the web based modules:

Each partner has produced modules on different topics for the e-learning platform done by every partner. A number of topics have emerged within the focus groups as of essential relevance for improving the quality of life of people with ID:

- **Emotional regulation and support for staff members working with older People with ID**
- **Person Centered Planning with older People with ID**
- **Communication and social networking of Ageing People with ID**
- **Taking Care: a complex professional stance**
- **Ageing Process**
- **Pathological Ageing in Elderly people with ID**

The objective of these products is to provide in-depth knowledge of elderly people with ID, their needs and the services they desire, directly linked with the improvement of quality of life of people with ID through better informed and trained support staff.

The creation of the project website

This is regularly updated with the projects' achievements, with the aim of dissemination through raising awareness, targeting policy makers, influencing service providers for people with disabilities through their care management agenda and services provided.

A press release has been regularly released talking about AGID achievements and including stories of the personal experience of support staff that have participated at the coordination meeting sharing their view of the value of these EU projects. These press releases have been distributed by ARFIE at an EU level to the majority of the representative bodies in Brussels working on social services and within the EU networks working in particular on disability issues.

The dissemination of the first AGID newsletter

Published on the internet website targeting support staff in particular. The above outcomes, the majority of which are still of confidential nature, have been regularly uploaded on the projects website <http://www.agid-project.eu/> within the members areas. Nonetheless based on these achievements, press releases for public dissemination have been regularly produced and disseminated.

4. Partnerships

The AGID project brings together, at a European level, various partners involved in the care and support of disabled people: it includes both social services providers and research institutes. The project has the benefit of the expertise of two university bodies, in the field of Disability Studies, and the experience of social services providers, from several European countries.

The aim of this consortium is to improve the quality of life of service users through the quality of staff training.

The Consortium has partners from 6 Countries: Italy, UK, Austria, Belgium, Luxembourg and France. Each of the participants has 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, and is balanced from many points of view. It is a mix of universities bodies and social services providers' organisations which ensure that the theory is 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 only a transnational approach, based on the experiences and knowledge of partners belonging to different cultural backgrounds and different ways of dealing with aging issues, can 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 capitalize on these networks to spread the outcomes of the AGID project.

Each WP of the project is 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)
- The partners from the University of Vienna and the University of Northumbria (De Montfort University) helped to develop the training modules' content and carry out their evaluation
- CADIAI will be in charge of the online evaluation of the training modules.
- ARFIE and Les Genêts d'Or will conduct the valorisation and dissemination of the results both during the project and at the end.

5. Future Plans

In the coming year we will be undertaking a two stage development process for the training modules, one being further development of the training modules through an Delphi expert consensus process and the other for at least 2 partners to carry out face-to-face testing of module delivery.

In addition to the 6 training modules developed from the 5 basic themes, a training guide has been produced offering information on the objectives of the training together with basic information on how to assimilate the basic principles of adult education; how to design and run a training session, how to make use of resources within the running of training and how to assess the impact of this training.

Once development of the modules is complete (WP3), WP4 – the delivery of the training module will take place through the development of an interactive web-based learning platform. It will be easy-to-use with clear instructions for learners. A “helpline” will be set up to answer the trainees’ queries. A range of technologies will be employed, including the use of interactive images, audio and video. Online quizzes and other interactive elements will be used to encourage self-assessment and a suitable e-portfolio utilised to monitor and manage a range of competencies and provide an online learning space for users to reflect, collaborate and share experiences.

The web based training modules will be based on case studies and will be evidence-based (empirical and practice-related background), with topics being those generated through the involvement of stakeholders.

WP5 will go on to pilot and evaluate the platform in all partners’ countries together with a template for the face validity of the web training which will be used by each partner in identifying the applicability, usefulness and impact on practice.

An evaluation questionnaire will be designed by the Consortium and incorporated within the web platform. Training certificates will be available to be downloaded after individual registration and successful completion of the training. The webmaster will provide all statistics on the participants who have undertaken the training program (anonymity and confidentiality will be maintained).

The last work package of the project – WP6- Valorisation and Dissemination has actually been carried out from the beginning of the project and will continue throughout its lifetime. The AGID website has been regularly updated with the project outcomes and with copies of issues addressed by the consortium within newspapers, academic journals, and service provider’s networks. The AGID e-newsletter has been published and a further three are expected before the end of the project. AGID final dissemination conference is expected to take place following completion of the project accompanied by a brochure and DVD with the project outcomes and recommendations. Project findings will be also presented at the next IASSID European congress. Last but not least is the continuation of the e-learning platform, for a further 5 years beyond the end of the project-major outcome of the project intended to demonstrate its sustainability since foreseen to disseminate the project outcomes for 5 more years once AGID has come to an end.

6. Contribution to EU policies

The life expectancy of people with disabilities is increasing and this poses a major challenge for the everyday support and care for people with intellectual disabilities (ID). Though ageing for people with intellectual disabilities has similar challenges and issues as for the general population, there are specific ageing related care issues for this group. Moreover, professionals in our health and social care services have very little knowledge and awareness of older people with intellectual disabilities who may have complex health and social care needs. Hence it is vital that the frontline staff and professionals have sound knowledge of their needs to provide personalised care and services.

The progressive aging of European Society is a matter of fact and is affecting the European Union as a whole, AGID considers the specific needs of people with disabilities and that delivering quality services is a major challenge facing our health and social care system. The AGID consortium believes that only a transnational approach based on the experiences and knowledge of partners belonging to different cultural backgrounds and with different approaches to deal with aging issues can produce effective and durable results at a European level.

The recent ratification of the UN-Convention on the Rights of Persons with Disabilities strengthens the need to address the perspectives of the Convention to the realities of older people with disabilities. The inclusion of all stakeholders in the Focus Groups is in line with a broad interpretation and application of the article 30 of the United Nations Convention on the Rights of Persons with Disabilities. This article affirms the right of people with disabilities to participate in political and public life, including 'Participation in non-governmental organizations 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'. The direct participation of people with disabilities in this European Project can be seen as a step toward the full enjoyment of this right.

European Institutions have been recognising the relevance of the ageing issue by launching several strategies and actions focused on disability and ageing. Thus, in line with the European Disability strategy 2010 – 2020, the AGID project intends to "Raise disability awareness and specific knowledge among health professionals, considering the specific needs of female and male patients" (Disability strategy 2010 – 2020). As highlighted by the Commission in the European Action Plan of 2003, "healthcare system are now called to give a new importance to the objective of enabling older and/or disabled people to live active, healthy and independent lives further into old age" (Commission Communication of 30 October 2003, Equal opportunities for people with disabilities: a European action plan).

Adequate research evidence on the complexities of care for older people with ID will be integrated into the training of professionals and frontline staff and shall be the fundamental contribution to the EU VAT system as also the EU platform for New Skills for new jobs. In line with the specific objectives envisaged by the Development of Innovation action, the AGID consortium will deliver innovative training opportunities for the frontline staff and health care professionals facing the new challenges of aging and disability. The envisaged results will be the improvement of staff knowledge and competences and consequently the quality of the services provided.

The AGID project directly addresses the priority 3 of LLP : "New skills for new jobs" since it focuses on the development of new skills for front-line staff. Participants in the project training modules will learn new approaches/practices/competences that will help them face the new challenges in their profession.

Among the Life Long Learning Horizontal policies AGID promotes equality between men and women and contributes to the combating of all forms of discrimination based on sex, racial or ethnic origin, religion or belief, disability, age or sexual orientation.

AGID will make a fundamental contribution to:

- Inclusion and person centred care for older for people with intellectual disabilities
- Collaboration and partnership working by the multi-professional teams and service agencies for providing person centred care
- Systems and processes for capacity building of the workforce in delivering personalised care for older people with ID
- Reflecting the UN-Convention on the Rights of Persons with disabilities in all the steps of the project.

The Consortium will help to improve the understanding and measurement of the users' needs. It will also find better ways to share research results and best practices, and disseminate this to staff working in all services.

Through this project, all partners will share policy and good practice, which will enable a common understanding of the significant issues in improving the quality of care for older people with ID as reflected in the training modules. This approach will contribute to the transferability and development of skills and knowledge amongst all the partners, our links and associated partner organisations.

Although not stated within the project application, AGID objectives reflect the priorities of the DG Health and Consumers, namely it intends to:

- Promote health: Actions under this section aim to foster healthier ways of life and reduce health inequalities, as well as to promote healthier ways of life and reduce major diseases by tackling health determinants.
- Generate and disseminate health information and knowledge: Actions under this objective aim to foster exchange knowledge and best practice on health issues and collect, analyse and disseminate health information.

Finally AGID will support some priorities of the DG Justice, Fundamental rights and citizenship, for instance the objective to combat any type of discrimination and through developing innovative and sustainable health systems, so that Member States can deliver more healthcare, with fewer resources, for generations to come. The impact of the project should enable access to better and safer healthcare for citizens, so that everybody can benefit from high quality care, regardless of who they are and where they live.

