AGID

DEVELOPING TRAINING MODULES
FOR STAFF ON AGING AND DISABILITY ISSUES

Development of a Web Based Training Program for Carers of Elderly People with Intellectual Disability

Project outcomes and achievements

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Published in May 2014

Contributions by and special thanks to the AGID Consortium:

Fondation A.P.E.M.H. (Association de Parents d'Enfants Mentalement Handicapés)
De Montfort University
University of Vienna, Faculty of Psychology
ARFIE(Association de Recherche et de Formation sur l'Insertion en Europe)
CADIAI Cooperativa Sociale
Association "Les Genêts d'Or"
ZONNELIED vzw
Northumbria University

The AGID Consortium would like to thank all the service users and their families for their contribution within the formulation, development and evaluation of the training without whom, the delivery of quality results within the AGID training platform, wouldn't have been possible.

Executive Editor

Dr Roger Banks - Consultant in the Psychiatry of Intellectual Disability (UK)

Published in May 2014

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Disclaimer:
The different nominations used such as: ageing, elderly and older people with ID are due to different terminologies in the respective partners' countries.

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Introduction to the AGID project

> ***“We are not victims of aging, sickness, and death.***
> ***These are part of scenery, not the seer, who is immune to any form of change.***
> ***This seer is the spirit, the expression of eternal being”***
>
> Deepak Chopra

Dr Roger Banks

Consultant in the Psychiatry of Intellectual Disability

United Kingdom

It is a widely acknowledged fact that in most developed countries we live in an ageing society. The number of people living into old age is increasing, there is a reduction in the birth rate, and moreover, there is a decreasing ratio of those of “caring age” to those who are older and in need of care and support.

This demographic change is also evident for people with intellectual disabilities who despite still having higher rates of morbidity and mortality than the general population are living longer as a result of advances in medical treatment and improvements in living standards and social care and support. People with Downs syndrome for example, who in the 1930’s had a life expectancy of only a few years are now living into their 50’s, 60’s and beyond.

There are therefore many new questions to be answered about the process and the experience of ageing with an intellectual disability. There have been a number of initiatives that have addressed this from an objective point of view. The World Health Organisation in its report of 2000 identified key issues as being:

- a lack of organized public or private sector systems designed to address the needs of persons with intellectual disabilities
- the need for changes in public attitudes in order to create positive and valued status for persons with intellectual disabilities
- improvement in public support for specialty services
- a need for supportive services, health surveillance and provision, and family assistance
- women with intellectual disabilities often being a disadvantaged class with little being done to address their specific health and social needs
- while intellectual disabilities may have a biological, genetic, or environmental basis, in some nations, they are still not distinguished clearly from mental illnesses
- health practitioners failing to recognise the particular problems experienced by persons with lifelong disabilities who are ageing

In addition to these broad principles which in many ways apply to people of all ages, other authors / organisations have identified more specific challenges that people with intellectual disabilities and their families encounter with increasing years.

Most significant is the fact that a large proportion of people with intellectual disabilities live with their families. As the individual gets older and parents age themselves the tasks of caring and support change both in their nature and in demand. Older carers can find themselves less able to provide the practical and physical support that is needed just as it may also be that their perceptions of the social and emotional needs of their family member are difficult to adapt and change. Families often find that the responses of statutory and other services do not reflect an understanding of these changing needs and dynamics, do not have a long term approach to planning for future care and are more likely to respond only in a crisis.

For those people with intellectual disabilities who live in residential care or supported community living, the knowledge, attitudes and skills of their carers is a vital determinant of the effectiveness of their support in enabling good quality of life and in being able to continue to "age in place". In other words, people with intellectual disabilities often find themselves being moved into different care settings when there is a significant change in their needs and carers are not trained or supported themselves to respond to the particular physical, psychological and challenges of ageing.

People with intellectual disabilities encounter the same issues of ageing as the general population but they may find themselves more vulnerable to service deficiencies, lack of awareness, prejudice and discrimination. This is particularly true in the case of access to timely, appropriate and high quality health care. This population has greater health needs in general and in those who have specific aetiologies for their intellectual impairment there may be particular health complications that might be encountered. Greater knowledge and awareness in health care professionals and the making of reasonable adjustments in health care delivery are essential. However, it is most often that it is family and professional carers who are the intermediaries in health care interactions. They need to know the kind of problems that may be encountered with age, how they might present and what they should be seeking in terms of assessment and intervention. Carers also need help in adjusting their roles to supporting individuals with longer term and disabling conditions.

Services and health and social care professional need to recognise that older people with intellectual disabilities are an increasingly diverse group. Longer life expectancy and changing population characteristics mean that there are more individual from black and ethnic minority communities and individuals with complex needs and profound and multiple disabilities. In planning for their care therefore there is an even greater emphasis on individualised, person-centred approaches to assessment of need.

It has been highlighted that people with intellectual disabilities face a "double jeopardy" as they get older. In addition to the stigma, discrimination and lack of individualisation that occurs in society and in services towards people with intellectual disabilities, they also face the prejudices and discrimination that occur towards the elderly.

To enable people with intellectual disabilities to live fulfilled lives with optimal quality of life and maximum autonomy, it is essential to listen to their views, their experiences and aspirations, their likes and dislikes as well as those of their carers. In the philosophy of co-production we should establish genuine partnerships between professionals, carers and people with intellectual disabilities that see everyone as being a resource, a source of experience, ideas and skills that can be brought together to achieve the best for all; the best for all being that which allows the spirit of the individual to grow and be sustained through to the end of their life.

The AGID project has used a method of appreciative inquiry to work with people with intellectual disabilities and their carers to establish their views on the key issues of ageing and from this to develop.

1. Developing Training Modules for Staff on Ageing and Intellectual Disability

1.1 Project Background: "Quality Services in an Ageing Society"

The progressive ageing of European society is an issue affecting the European Union as a whole. Additionally, the life expectancy of people with disabilities is increasing and this poses a major challenge for the everyday support and care of people with intellectual disabilities (ID). Though ageing brings similar challenges and issues as for the general population, there are specific ageing-related care issues for people with ID. Most people with ID have a need for support throughout their lives; with increasing life expectancy the numbers of older adults with ID continues to expand and community agencies and families now face the challenge of providing supports as these adults experience age-related changes. In comparison with adults without long-term disabilities, adults with ID are more likely to experience earlier age-related health changes, limited access to quality health care, and fewer financial resources. In addition, they are more likely to be living with parents into adulthood and to have limited social supports and friendships outside the family.

Moreover, professionals in health and social care services have very little knowledge and awareness of the both the "everyday" but sometimes complex health and social care needs of this group of people. The AGID project considered the specific needs of ageing and elderly people with intellectual disabilities, and believes that it is of primary importance that the frontline staff and professionals acquire sound knowledge of these service users' needs in order to provide personalised care and services.

General principles and standards for policies and services for adult and ageing persons with intellectual disability

Marco Bertelli & Niccolò Varrucciu
CREA - External Evaluator

The United Nations Convention on the Rights of Persons with Disabilities covers all persons with disabilities "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". Within the Convention, there is scant mention of ageing as a specific issue facing persons with disabilities. Two articles however stress the need to prevent age-related disabilities (art.25) and to promote the social inclusion of older persons (art.28). Other relevant articles in the Convention relate to living independently and community inclusion (art.19), mobility (art.20), respect for home and family (23.2), education (art.24), health (art.25), habilitation (art.26), work and employment (art.27), adequate standard of living and social protection (art.28) and participation in cultural life, recreation, sports and leisure (art.30). In line with the UN Convention public policies of many European countries have increasingly supported the rights of people with disabilities to freely choose where to live, although it has not always been followed by an actual increase in environmental supports to allow full community participation.

Key challenges that must be addressed by communities, families, and adults aging with ID include:

- improving the health and function of adults aging with ID and their families
- enhancing consumer directed and family-based care
- reducing barriers to health and community participation

The majority of people with ID live with family or independently but a considerable number have lived most of their adult lives in staffed residential situations and rather than being employed have attended specific workshops and day programs. There is a strong likelihood that as adults with ID get older they will have small social networks and that paid staff will have significant roles in those networks often occupying personal and friendship roles equivalent to those usually seen in family members.

In some countries, not only rehabilitative services, vocational opportunities, and quality old-age services are not provided but also older adults with ID are still disregarded, marginalised or institutionalised; housing is often inadequate.

Older adults with co-morbid physical and/or mental health conditions experience particular problems and their often complex comorbidities are not addressed. Across the world national health provision schemes are often inadequate and do not recognise the special needs of adults with ID and as they age, their health needs are not attended to in a manner equivalent to that of the general population. Specialist services for people with ID are not available, further compromising their health and potential longevity. In addition, lifestyle choices and inadequate personal skills may have a major impact on their health and well being. Sensory and mobility impairments, obesity, poor oral hygiene, and certain lifestyle or personal attributes can also contribute to difficulties.

In its work plan of 2008, Inclusion Europe set out to collect, analyse and publish information about disability training of mainstream social services staff. Reports from most EU countries showed that unfortunately there is very little of this kind of training available. Therefore the members of the Working Group on Social Exclusion of Inclusion Europe have developed some general principles and basic standards to improve the accessibility of mainstream social services and public administrations.

Self-determination, universal access and equal citizenship are the fundamental principles that must guide all efforts towards access to mainstream social services for people with ID. Access to these services is often determined by the accessibility of public administrations as the first and foremost point of contact for every citizen. Accessibility in this context is not only limited to physical aspects but also to how understandable services are for everybody, as well as the attitudes of staff in terms of being welcoming and receptive to the special needs of all their clients. Accessibility also requires the simplification of formalities and procedures and avoidance of possible contradictions and overlapping.

In a human rights-based approach the citizen should be considered as the essential protagonist and attention should be paid to:

- Placing the citizen at the centre of public services
- Responding to the needs of the user
- Strengthening the social and health care systems
- Changing laws and rules correspondingly
- Promoting adequate financing and joint responsibility
- Guaranteeing proximity in management and in provision
- Non-discrimination

The BIOMED-MEROPE project (2000) indicated that although the intention of most European Countries is to promote the principles of inclusion into community care and to ensure health services in more appropriate settings, the specific needs of people with ID have yet to be addressed fully at a legislative level. The same gap is present with respect to the right to a good quality of life.

With the widespread acceptance of deinstitutionalisation, debate has focused on who should provide services in general for people with intellectual disability. In Austria, Greece, Ireland and Spain there has been an increased reliance upon family, voluntary organisations and private initiatives as long-term providers of care.

In England the Department of Health (DoH) has noted that specialist facilities and services might be required for those who are mentally ill, have behaviour problems or offend but they also recommend that people with ID should use ordinary services whenever possible. In 1996 the Royal College of Psychiatrists recommended the development of specialist mental health teams to ensure coordinated services and effective liaison and integration with other agencies. These teams should have expertise in both ID and mental health, should provide direct services to patient and carers, and offer trainings to other agencies. Yet, exemplary government policies and practices in health surveillance, provision and promotion, and formal schemes for social and family supports, as well as rehabilitative, training, and personal supports in respect to ageing people with ID do exist.

The Australian Institute of Health and Welfare found that many of the problems of meeting the day activity needs of people ageing with an ID are related to the structure and models of service provision. In Ireland Government policy in relation to Day Care and Employment for Adults focuses on the need to promote the employment of ageing people with ID through vocational training programmes, widening of the use of sheltered employment provision and promotion of open employment opportunities; and the need for day care programmes to be provided in small local units. Until 2004 over half of the people aged 65 or more with an ID attended a day service other than programmes for the elderly.

People with ID who are ageing have particular needs in relation to accommodation:

- they are more likely than the general population to have low levels of functional ability, which is often the main reason they require care, particularly residential care
- many people with an ID have never been married and therefore have no spouse or children who are the main source of informal support to older people with a late onset disability
- those relying on informal support from aged parents or carers are at risk of losing this
- they are less likely than the general population to be homeowners

Rather than exercising choice about the location, type of accommodation, and selection of co-residents, adults with ID leaving the family home in mid-life may be forced to take the only option available. Some are likely therefore to be ageing not only in a group home, but one which they have not chosen and which is a poor match to their needs.

Government policy in the Republic of Ireland (Review Group on Mental Handicap Services, 1990) identifies enabling people to continue to live at home as an important objective in the provision of services to people with intellectual disability. The supports required to achieve this objective should be flexible and operate at weekends and during unsocial hours. Group homes were identified as an appropriate option for those who need to leave the family home, with placement in a residential centre as the least favoured option. There has been a significant increase in the proportion of people who using community group home accommodation and nursing home services and a decrease in the use of village type/residential centres and psychiatric hospitals.

Government policy in relation to the provision of services to people ageing with an ID highlights the need for adaptation of facilities to cater for changing needs (Review Group on Mental Handicap Services, 1990). On retirement, intellectually disabled persons in supervised accommodation should continue to live in their place of residence and have the option of attending an appropriate facility for elderly persons on a daily basis (Review Group on Mental Handicap Services, 1990). The location and resourcing of residential units may have a major impact on the ability of people with intellectual disability to access alternative day activities following retirement.

The Regional Disability Services Unit of the North Eastern Health Board suggests that Health Policy for the delivery of services to older people with ID should aim at ensuring easy access to appropriate assessment, diagnosis and treatment services in order to support older people in maximising health and social gain. Access to screening services, primary care services, acute hospital services, psychiatric services and health promotion activities should be promoted through targeted programmes and information in easy to read and accessible formats. Awareness of particular age-related conditions that affect people with ID such as dementia should also be promoted.

The National Intellectual Disability Database, the planning tool for services for people with ID in Ireland, does not identify retirement as a main day activity for people with intellectual disability. As people age, there is a requirement to plan for their retirement or the restructuring of their daily occupation through person-centred planning to meet their changing needs. This may include accessing community run services for older people, increasing leisure activities, a change in focus from the acquisition of vocational skills to maintaining previously learned skills and facilitating a person to engage in home based activities during the day.

Supports to ensure that people with ID can remain in a home setting for as long as possible should be strengthened. Planning for the future accommodation needs of people with ID living at home is essential in order to avoid crisis or emergency placements. Information on the options available to the person with an ID should be easily available and discussed in the context of person-centred planning.

In 2004 Irish Government launched the Disability Strategy, which is having a major impact on both the planning and provision of services to people ageing with an ID in the future.

In Australia over the last decade, community and aged care services have expanded to support older people to age in place, in their own home in the community. The Home and Community Care program provides low levels of in-home support, while programs such as the Community Aged Care Package provide the equivalent of low care residential support to people in their home. Population-based targets have been set for the provision of residential aged care, and access is controlled through Aged Care Assessment Services (ACAS) (AIHW, 2005a, 2006a).

The most comprehensive review of policy in relation to ageing was undertaken by the World Health Organisation (2001) in association with an "expert" group of researchers drawn from the International Association for the Scientific Study of intellectual Disability (IASSID). Their report identified a number of policy guidelines:

- Age related change appears to occur when people with ID are in their fifties although premature ageing can be present in persons with profound and multiple disabilities and frequently in those with Down Syndrome. Moreover life expectancy is shortened by poor health status and poverty. Hence planning and provision for people with ID cannot be based solely on chronological age cut-offs.
- Throughout the life span, public policies should be supportive of healthy ageing with opportunities for older persons to remain socially active and contributing to their well being. This should reduce the burden on health and social care services resulting for higher levels of dependency over a prolonged period of old age.
- Ongoing research and evaluation is required to identify effective intervention programmes to promote healthy ageing within three broad domains:

  - maintaining functional abilities and extending competence in later life

  - enhancing older people's quality of life (notably in residential care)

  - identifying the factors that promote increased inclusiveness with society.
- The needs of people with ID should not be cut-off from the wider field of ageing. This avoids duplication of services, encourages the sharing of expertise and in rural areas in particular, assists with maintaining people within their local communities. This policy objective requires the development of common infrastructures for accessing services, shared training for professionals and the wider public. However it was acknowledged that specialist resources should be available to which clinicians, families and carers can seek information, referral and training.

With regard to the particular issue of dementia and people with ID, an international round-table drew up what has become known as the "Edinburgh Principles" (Wilkinson & Janicki, 2001). These define internationally applicable working practices for community supports for adults with a learning disability who have Alzheimer disease based on the above policy guidelines:

1. Adopt an operational philosophy that promotes the utmost quality of life of persons with intellectual disabilities affected by dementia and, whenever possible, base services and support practices on a person-centred approach.
2. Affirm that individual strengths, capabilities, skills and wishes should be the overriding consideration in any decision-making for and by persons with intellectual disabilities affected by dementia.
3. Involve the individual, her or his family, and other close supports in all phases of assessment and

services planning and provision for the person with an intellectual disability affected with dementia.

4. Ensure that appropriate diagnostic, assessment and intervention services and resources are available to meet the individual needs, and support healthy ageing, of persons with intellectual disabilities affected by dementia.
5. Plan and provide supports and services that optimize remaining in the chosen home and community of adults with intellectual disabilities affected by dementia.
6. Ensure that persons with intellectual disabilities affected by dementia have the same access to appropriate services and supports as afforded to other persons in the general population affected by dementia.
7. Ensure that generic, cooperative, and proactive strategic planning across relevant policy, provider and advocacy groups involves consideration of the current and future needs of adults with intellectual disabilities affected by dementia.

Many older persons with ID are now living with family carers and indeed may outlive their parents. Mencap (2002) among other organisations, has highlighted the extra future demand that will fall on services. The Commission for Social Care Inspection (CSCI, 2007) in England found many local authorities were failing to plan for this ageing group. The Department of Health in England (2010) through their Valuing People Strategy have placed particular emphasis on policy initiatives in relation to older carers of persons with learning disabilities. They note that an estimated one in four older families with a family carer aged 70 or over was unknown to services, until there was a crisis, such as the family carer becoming ill or dying. In these circumstances service responses can be limited and often inadequate as nothing has been established in advance. Moreover the family members at times of crisis are often worried and distressed. The result is often a service response that nobody would ideally have chosen, for example admission to a residential centre or nursing home (Kelly & McConkey, 2011).

This also raises the issue of "re-institutionalisation" of people with ID in later life as health and support needs changes and service commissioners seek cheaper options for service provision. A report by an international panel of experts (IASSID, 2010) identified improvements in support services for ageing carers:

- Services should combine expertise from different sectors, such as older people's services, advice services and/or voluntary organisations supporting older people or people with a ID
- Greater advocacy for older family members, both for the person with an ID and for the older family carer
- Information (in different formats) that explains the older families' options for support at the moment, in emergencies and in the longer term
- Training and improved awareness for people working in different sectors in older family issues, and fuller explanation of the options for supporting them (this is often most effectively delivered by older families themselves, either in person or through a DVD presentation).

1.2 Aims and Objectives

Daniela Janeva
AGID Project Coordinator

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 intended 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. This is done by providing a structured and practical package of training modules for front-line staff, adapting the spirit of the United Nations Convention on the Rights of Persons with Disabilities (UN-CRPD)[1].

By increasing knowledge and competence this training aims to help recognise pre-empt, prevent and handle problematic age related challenges, and as a result improve the quality of the services provided. It is intended that the quality of life of elderly people with intellectual disabilities and their families will be improved through the 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.

Moreover, AGID has 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 aimed 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. The training modules, based on the outcomes of focus groups involving service users, will increase the 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 aimed to develop high quality and innovative staff training on specific issues related to aging and disability, through the development of innovative practices at EU level that would consequently be better disseminated and utilised at Regional and EU levels.

- *Developing Vocational Skills taking into consideration the labour market needs - "New Skills for New Jobs Platform"*

The project directly addresses this priority through its focus on the development of new skills for front-line staff. Participants in the AGID project training modules have learned new approaches; practices and competences that will help them face the new challenges in their profession.

The AGID project also addresses the following LLP "Horizontal" policy:

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.

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[1] http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf

1.3 The AGID Consortium

The Consortium involved in the AGID Project comprises 7 organisations, both from different backgrounds (university bodies and social services provider organisations) and from different countries.
The following summary details the organisations' breadth of experience on the issue of ageing and intellectual disabilities and their roles within the Consortium:

Fondation A.P.E.M.H. (Association de Parents d'Enfants Mentalement Handicapés) is a national NGO working in Luxembourg for the support of people with intellectual disabilities, multiple disabilities and dual diagnosis. The principal aim of the association is to improve the quality of life of their client groups and to ensure their social and vocational inclusion. A.P.E.M.H. has numerous services in various areas, such as residences, educational support structures to enable people to live in the community, sheltered workshops and a training centre **UFEP** for professionals in the field.

De Montfort University (DMU) is based in Leicester, England, UK and boasts 13 National Teaching Fellows, higher education's most prestigious teaching awards. This is one of the highest numbers awarded to any university since the scheme began in 2000. The University's pioneering research, driven by over 1,000 research students and supported by 500 staff, is internationally renowned and addresses some of the most critical issues affecting our world. Subject matter experts and distance learning development staff in the Faculty of Health and Life Sciences are contributing to this project.

The University of Vienna is the largest teaching and research institution in Austria. The project partner is the department of clinical psychology, which has a special focus on research topics in the field of intellectual disability and aging. The partner has a high competence in designing and offering training courses, in designing research and evaluation, and in dissemination activities (publications and conferences). They also have broad experience in jointly developing curricula and training modules especially in the context of EC funded projects.

ARFIE - Association de Recherche et de Formation sur l'Insertion en Europe brings together at European level various partners involved in the care and support of disabled people, associations of and for disabled people, training bodies, researchers and professionals all working in initial and continuing training; ARFIE is a member of the European Disability Forum and has been involved in organising training modules for professionals working with people with disabilities. It has also held conferences and issued reports on various important issues in the disability sector. The role of ARFIE was mostly focused on dissemination of the project outcomes through its European network (EDF and Inclusion Europe).

CADIAI
COOPERATIVA SOCIALE

CADIAI Cooperativa Sociale is a social cooperative and is an agency managing services to disabled. It has also assisted many persons in the difficult transition to aging. CADIAI has created a work group called "Disabled become Old" composed of an expert in training process, a pedagogue and two researchers of the University of the Studies of Bologna. Since its foundation in 1974, CADIAI has operatedin the area of services to the elderly, in domiciliary, semi residential and residential services.

LES GENÊTS D'OR
Passionnément solidaires

Association **"Les Genêts d'Or"** was created to promote the establishment of structures to meet the needs of rural families in the department of Finistère (France). Its statutes define its purpose as the recognition, hospitality, support and integration of persons with disabilities and dependent people. It currently manages 24 properties, hosting over 1500 people and conducts studies on the aging of the population. It also provides both individual and group responses to particular situations.

Zonnelied vzw
dienstverlening voor
mensen met een handicap

ZONNELIED vzw is a national NGO working in Belgium for the support of people with an intellectual disability, multiple disabilities and dual diagnosis. The principal aim of the association is to improve the quality of life of their client groups. They have numerous services in various areas, such as residences, day care center and supported employment. ZONNELIED vzw has been working for 30 years as a service provider (home, work, leisure, education, health, support...) and has been faced with the growing challenge of aging of people with disabilities.

northumbria
UNIVERSITY

Northumbria University is a leading Higher Education Institution based in the North East of England. The University offers almost 500 courses on either a full-time, part-time or distance learning basis, at foundation, undergraduate, postgraduate/masters and doctorate level. Research and scholarly activity is at the very core of Northumbria's academic community.

Northumbia has been replaced with De Montfort University.

1.4 Introduction to the Methodology: "Appreciative Inquiry"

Ann de Winter
Coordinator of Mediander

The innovative character of the AGID project is based on the use of the Appreciative Inquiry (AI) methodology. This model was used in the focus groups with the aim of conducting as assessment of the social and health care needs of ageing people with disabilities, through the inclusion of a wide range of stakeholders such as: users, families, front-line staff, health professionals and policy makers within health and social services. The results of the focus groups became the pattern for developing and delivering the training modules.

Appreciative inquiry is based on principles of inclusion and enables the voices of users, families and professionals all to be heard equally. This qualitative methodology of research is a simple but radical approach to understanding the social world. AI concentrates on exploring 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 on – the emphasis is on appreciating the activities and responses of people rather than concentrating on their problems. In addition it also facilitates discussion and exploration of practice, as it starts from a positive assumption that every human system already has strengths: key factors of health and wellbeing.

The AGID consortium decided to use this method because:

- AI is a **collaborative effort** to bring people together, it involves multiple members or stakeholders conversing and working together.
- AI is **inclusive,** it invites a widening circle of voices, representing all stakeholder voices within a system.
- AI is **generative,** it fosters a dialogue that cultivates scenarios and theories that lead to further cooperation, to higher performing work. Participants are drawn to work together toward a shared goal.

The AGID project has been conducted incorporating the four principles of Appreciative enquiry (AI):

1. Discovery – appreciating what gives life, when we are at our best, positive core
2. Dreaming – envisioning what might be, images of the future we want
3. Designing – Determining what will be and
4. Delivery – Planning (creating) what will be

Discovery

At this stage we identify the whole system around ageing people with intellectual disabilities and bring together all the stakeholders, service users, family carers, front-line professionals, trainers, to work in focus groups; immediately giving everyone a voice in the process which begins when participants interview each other with appreciatively focused questions on the key factors of health and wellbeing.

Dream

In the dream phase, people imagine new dimensions, outcomes and results.
Based on the common success factors identified, we develop a common dream.

Design

The design phase addresses the question: What kind of organisational forms, policies, and structures will enable the cooperative capacity necessary to make these imaginative outcomes and highest aspirations become a reality. Designing involves creating the foundations upon which guiding structures are built.

The design phase begins the transformation from stories, dreams, ideas and feelings to actions and projects. These ideas are the key elements on which to build the different modules.

Destiny

The Aim of the destiny phase is to ensure that the shared dreams can be realised through the "blueprint" of desired actions / outcomes. To do this, participants in Ai do specific action planning, and role allocation for the necessary next steps.

1.5 Project Development and Implementation

Daniela Janeva
AGID Project Coordinator

The project development was designed as follows:

I. Identification of User Requirements

- Carrying out focus groups in order to identify user requirements; this process has included:

  - People with ID
  - Their families
  - Carers for older people with ID
  - Health professionals

II. Development of Modules

- Development of six training modules based of the identified user requirements
- First evaluation of the modules by means of a Delphi Process and trial trainings in face to face sessions

III. Development of an Online Training

- Adapting the modules for the use in an online training program
- Providing the adapted training program on an online platform

IV. Evaluation

- Carrying out a trial run in all partner countries
- Evaluation of usability and learnability of the platform

V. Valorisation and Dissemination of the training program

The project management of the AGID has been undertaken by the promoter: La Fondation A.P.E.M.H. (Association de Parents d'Enfants Mentalement Handicapés) in collaboration with the work package coordinators to ensure: monitoring of tasks undertaken, that the work program is adhered to both in terms of timing and quality of the outputs, and to ensure that the results of the work packages are suitably integrated with the other outcomes and in line with the project's aims' and objectives.

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, an internal evaluation has been conducted among partners by means of a questionnaire in order to assess their level of satisfaction during the development of the project and to shape the continuation of the project according to this feedback. In addition, an external evaluation process provided on-going support and reflection during the project development.

The first milestone of the project was the conduction of assessment of users' needs through the use of the appreciative inquiry methodology within the focus groups.

The whole consortium received by Zonnelied a two day training in the methodology and its theoretical framework (together with a handbook) with the aim of guaranteeing uniformity in the composition and conduction of the focus groups in the different countries and the conformity of the outcomes.

A questionnaire on complex social and health care needs was distributed to all partners in order to guarantee standardisation of the outcomes and enable comparability between the different cultures and backgrounds.

Each partner was responsible for carrying out 2 focus groups (Discovery and Dream-design) involving users, family careers, professionals using the AI methodology; 171 individuals participated in this needs assessment. The focus groups allowed direct involvement of the people with ID and their families within the formulation of the training and have represented great opportunities for people with ID to become direct participants within EU projects.
Each partner produced an Appreciative Progress Report which were analysed and summarised the within final report of all the focus groups conducted by the partnership.

This process of data collection was a very important step as the basis for the creation of the training modules for the professionals supporting people with ID.

Six topics were identified for the training modules:

1. The Ageing Process
2. Person- Centred Planning
3. Social Networking and Communication of Elderly People with ID
4. Emotional Regulation for Front-line Staff
5. Pathological Ageing in Elderly People with ID
6. Taking Care: a Complex Professional Stance

The objective of this work package (coordinated by University of Vienna) was to develop high quality training content and a learning platform that will provide better knowledge for support staff and professionals. Once the first draft of the modules had been produced by each partner and the whole Consortium had derived a common curriculum, a two-step- testing process took place. Firstly by experts during a Delphi process and secondly each module was assessed by at least 2 partners during face-to-face testing of the modules.

The purpose of the Delphi process was to bring an established research tool into the generation of a consensus between expert consultants in the field, and hence to validate the topics being prioritised within the training platform. Delphi experts' feedback provided essential support for the AGID team in optimising the modules before being transformed into an online training program.

Following this a face to face testing with professionals directly concerned with the subject content was conducted in each country.

These sequences based on two modules (partners working in pairs, each testing their own module and a module from another partner) were used to verify the adequacy of the content of the training, and whether the training matched the users' and the professionals' needs and expectations.
The fourth part of the work programme (WP-IV) was concerned with delivering the training modules (coordinated by DMU University) designed by the partnership in e-format, and the related e-learning platform. The key aspect of this work package was the development of an interactive web-based learning platform in English, French, German, Italian and Flemish. The platform needed to be easy-to-use, using evidence-based material, and with clear instructions for learners. A range of technologies have been employed, including the use of interactive images, audio and video. On-line quizzes and other interactive elements have been used to encourage self-assessment and a suitable e-portfolio can be built up to record and demonstrate a range of competencies as well as an online learning space for users to reflect, collaborate and share experiences.

Once the online training platform had been developed and available, the closing step of the AGID project was to evaluate if the e-learning modules (coordinated by CADIAI), as implemented in the online platform, are useful in helping front-line staff in improving their knowledge and competencies related to the work with aging people with ID. The concept of 'usability' of an e-learning product was evaluated using analyses based on two commonly used rating scales: the Software Usability measurement Inventory (SUMI) a 50-item questionnaire measuring five aspects of user satisfaction (Likability, Efficiency, Helpfulness, Control and Learnability) and the System Usability Scale (SUS) a 10-item questionnaire giving an

overall satisfaction score. The questionnaire has been built with the aim of maximising the feedback from the users, providing both quantitative and qualitative data about user feedback, while remaining short and quick to administer.
In addition to the above, demographic and other data were collected including years of work experience, educational level, general and specific computer experience and previous experience with this or similar products. These socio-demographic variables enabled the identification of specific user profiles which could tailor adjustments to the user interface where necessary.

The dissemination and valorisation strategy for the project had three main directions (coordinated by Arfie & Les Genêts d'Or): dissemination for awareness, for understanding and for action. AGID results and outcomes have been disseminated through the website and training platform, newsletters, articles in specialised on journals on ID, through presentations at different conferences / world congresses on Intellectual Disability and through a variety of other dissemination activities, roundtables, conferences, workshops and policy consultations on ageing and social services within the EU.

1.6 User Involvement

Daniela Janeva
AGID Project Coordinator

Professor Raghu Raghavan
De Montfort University, Leicester

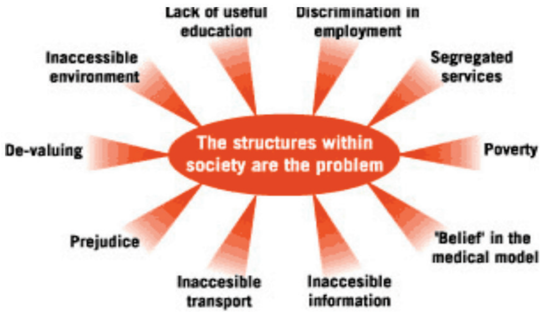
The active participation of people with ID in the AGID project is in accordance with Articles 29 and 30 of the UN-CRPD which affirms the right of people with disabilities to participate in political and public life, including 'participation in non-governmental organisations and associations' with the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



Disabled people as active fighters for equality working in partnership with allies.

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 means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change" [2]

Co-production defines people who use services as assets with skills rather than a demand or drain on resources, it

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[2] The new economics foundation/NESTA (2009) The Challenge of Co-production

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. (see 3.5)**

1.7 Results of the Focus Groups on Needs Assessment

Zonnelied

Feedback from the focus groups consultation was grouped around three main themes:

- **autonomy in daily life (irrespective of age)**
- **having the material means for minimum comfort and for a life with dignity**
- **the need for social relationships**

Marked similarities were observed between the French and Italian groups regarding notions of freedom of choice and life lived outside of institutions. The northern countries' participants accorded more importance to the collective aspect, considering this as the basis of the social links necessary for maintaining the individual's balance of needs.

The key points identified from the focus groups that determined the training content were:

Emotional regulation and support

For staff members

- Specific issues related to old age
- Grieving
- Dementia related issues: assessment and diagnostic skills
- Coping with stress
- Relaxation techniques
- Mindfulness techniques
- Coping
- Avoiding burn-out
- Problem-solving techniques
- Handling emergency situations

For service users

- Age-related critical life events
- Support with bereavement, loss and grieving
- Specific relaxation techniques as individual resources for coping with stress

Person Centred Planning

- What does it mean?
- How do we use it (tools) in the work with aging people with ID?
- How as a member of frontline staff can one emphasise personhood for older people with ID
- Individualised planning
- Social activities
- Social support
- Outcome measures
- Understanding what quality of life means for people with intellectual disabilities

Relationships and communication

- Learning to network in mutuality
- Learning how to communicate with an older person with ID to ensure mutuality

Care management: Designing care/support for older people with ID together

- "Ageing in place"
- With whom? Who is making the decision?
- How to discuss it
- How to realise and organise the right care and support
- Using individuals' biographies and reminiscence as a means of ensuring the "best fit" of support/care (establishing best interests for older user by referring to his or her past experiences).
- Dignity of care
- Practical issues such as food, money
- Coordinating different services, agencies and health care professionals
- Health and Social Care policy in the working environment
- How health and social care policy is related to value based care and services
- Service development for older persons with ID
- Service evaluation for older persons with ID
- What is the impact of health and social policy on everyday service provision?
- User involvement and front line staff involvement
- Ethics and values of work

Age related health issues in people with ID: Normal and Abnormal Ageing

- Knowledge about normal processes of ageing
- Observation of age-related change
- Knowledge about presentation and prevalence of disease in elderly people
- Knowledge about prevention strategies
- How to react to physical emergency situations
- Facilitating access to health care
- Training on attitudes - changing attitudes and relationship towards the aging person with ID
- Methodology: Role Play, Video

1.8 EU Disability Strategy 2010-2020 and UN-CRPD within AGID

Daniela Janeva
AGID Project Coordinator

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:**[3] *"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 training for the staff.

- **Equality:** *"combat discrimination based on disability and promotes equal opportunities."* AGID aims 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-centered way. Article 8 of the UN CRPD is concerned with awareness-raising and the AGID training platform raises awareness[4] 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 their rights should have a positive impact on the effective implementation of the UN CRPD.

- **Social protection:** *"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.

- **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"*[5]

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[3] ec.europa.eu/justice/discrimination/disabilities/disability-strategy/index_en.htm

[4] un.org/disabilities/convention/conventionfull.shtml

[5] un.org/disabilities/convention/conventionfull.shtml

2. Development of the Training Platform

2.1 The Content Development of the Modules and Training Manual

The development of the content of the training platform endeavoured to achieve 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.

From the consultation and discussion described above, the consortium derived a common curriculum divided into modules:

• Module I	The Ageing Process
• Module II	Person Centred Planning
• Module III	Social Networking and Communication
• Module IV	Emotional Regulation for Front-line staff
• Module V	Pathological Ageing in Elderly People with Intellectual Disabilities
• Module VI	Taking Care: A complex Professional Stance

Following this identification of the topics on which the training modules were to be built, each partner took responsibility for developing proposals for their structure and content.

The overall structure of each module included aims, content description, plan of training, evaluation questionnaire, references and resources. The modules also included contextualised narratives of users and carers and reference to policy development.

Each proposal addressed the following key issues:

- the complex health and social care needs of older people with ID
- the knowledge and skills to plan and deliver appropriate models of care
- working with multiple service agencies and professionals
- person-centred planning
- human rights and health and social care policy.

The establishment of this common curriculum was followed by a two-step testing process, by a group of experts using the Delphi method and by at least 2 partners during face-to-face testing of the modules.

The Delphi process is a structured communication techniques that aims to achieve a consensus view from a panel of experts through two or more rounds of questioning. The Delphi process for AGID was designed in three rounds, each of them with specific objectives. This process enabled the AGID team to optimize the modules before being transformed into an online training program and validated their currency, application and originality.

Face-to-face testing of modules by professionals directly concerned with the subject was conducted in each country. These sequences involved partners working in pairs, each partner testing their own module and a module from another partner, and were used to verify the adequacy of the content of the training, and if this matched the needs and expectations of service users and professionals.

2.2 Training Guide

Mag. Andreas Kocman & Univ.-Prof. Dr. Germain Weber
University of Vienna, Faculty of Psychology

The Training Guide 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.

Adult Education

Six principles for successful training are identified which are applicable to both face-to-face and on-line training:

1. **The principle of respect for the adult in training:** Every carer has limits to their learning abilities and their own way of integrating new information. The speed at which they learn this information plays an important role in the way they process and integrate the elements of the training.
2. **The principle of receptiveness:**
   A meaningful learning process begins with the will and the desire to learn. To ensure this receptiveness, front-line staff should be made aware of the benefits of the training and helped to understand the reasoning behind it, in order to make the information which is presented to them their own.
3. **The principle of interaction:**
   In the case of front-line staff, former training and experience forms the basis on which new knowledge is integrated. Consequently the educational methods should encourage exchange between the trainer and the participants and between participants themselves.
4. **The principle of facilitation of the learning process:**
   Educational systems should respect certain factors essential to the acquisition of knowledge, skills and behaviours. This means that the content should be structured and easy to understand, make use of exercises of appropriate length and follow an appropriate pace.
5. **The principle of acquisition, assimilation and retention of knowledge:**
   Learning achievements should be assessed before, during and after the training process in order to judge its effectiveness...
6. **The principle of innovation:**
   Educational mechanisms should be provided that involve staff in the learning process, give clear analysis of the learning experience and enable the individual to find out what their most effective learning practice is. These can include group work or individual solitary learning.

The modules were designed to be carried out as online training. However, it is also possible to conduct them in a team together with a trainer.

When conducting face-to-face training, trainers need to bear in mind that:

- The training is modular; each module can be completed on its own.
- Each module is divided into three to four subtopics.
- Training should ideally be divided into sessions of 90 minutes with 15 minute breaks in between.
- It is also important to devise a schedule that fits best the needs of your participants.
- Inform your participants before you begin about the schedule, the aims of the training and the learning outcomes of the training

- You should convey information in a way that everyone can follow, understand and learn
- You should encourage participants to interact and exchange ideas with each other to work out new courses of action and to improve their professional practice.

Organisation of the Training Session – Online Training

The e-learning version of this training enables staff to access learning opportunities at times and places that best fit their lives. This means access to knowledge and learning resources around the clock, from places that are most convenient for individuals and groups. People who acquire knowledge about complex and challenging topics with a computer-based learning environment typically make use of various self-regulatory processes such as planning and setting goals, knowledge activation, monitoring one's own progress.

Before beginning a training session participants should:

- Analyse the learning situation - How much is there to do?
- Set meaningful goals - When, where, how much? – write them down and cross them out once achieved
- Determine which strategies to use given the task conditions - What is the best way for me to study? [6]

During the learning process, participants should:

- Assess the effectiveness of the strategies used - are the expected outcomes those that are actually achieved?
- Evaluate their understanding of the topics learned

A combination of formal and informal learning situations can support each other to achieve better learning outcomes. If a number of trainers in the same facility start the online-training together, notes about the exercises in the training can be compared, difficult sections in the training can be discussed, the development of a change in behaviour towards difficult situations can be noticed and shared. If immediate problems arise in the work place, relevant sections in the training modules can be revisited to provide information and suggestions. Learning is more effective when it can be applied to real situations.

2.3 Module I "The Ageing Process"

Professor Raghu Raghavan

De Montfort University, Leicester

The main aim of this module is to provide professionals and frontline staff with knowledge about the ageing process in general and to focus on how this affects people with intellectual disabilities. The module also explores the biological/ psychological and social issues concerning ageing as also examine healthy and successful ageing perspectives.

Ageing is common to all living beings and disabled people are no exception, indeed ageing may have greater impact on their disability and they may lose what autonomy they possess due to the impairment of their various skills and faculties.

Section 1 – What is ageing?

This defines the ageing process and introduces theories of 'good' or 'successful' ageing. Using case scenarios and reflective exercises, participants learn about:

- The ageing process
- Good/successful/active ageing
- Active ageing in intellectual disability

Section 2 – Social Construction of Ageing

Discusses our societal views of the elderly and how society makes provision for them. This will include:

- Ageism and discrimination
- How ageism affects service provision
- How we can rectify this

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[6] **Azvedo, R. (2007).** Understanding the complex nature of self-regulatory processes in learning with computer-based learning environments: an introduction. Metacognition Learning, 2, 57-65.

Section 3 – Policy on Ageing

Addresses the need for policies that protect the rights of older people:

- Human rights challenges
- Implications of policy on practice

Section 4 – Ageing and Intellectual Disability

Provides an insight into the issues specific to older people with intellectual disabilities and how we can support successful ageing amongst this group:

- Key and common issues in ageing and intellectual disability
- The support-outcome model for successful ageing for people with intellectual disability
- Implications for practice

The module concludes with a summary of the important issues and a post-module assessment of the knowledge you have acquired.

Successful completion of the module should result in acquisition of the following competencies:
- Ability to reflect about ageing and ageing process
- Ability to understand the theoretical approaches to ageing and its strengths and limitations
- Recognition of healthy active ageing for people with ID
- Ability to communicate about ageing process to professional and service colleagues and also to people with ID and their families

2.4 Module II "Person-Centred Planning"

Fondation A.P.E.M.H.

The first part of this module gives an introduction to this relatively new approach in the support of persons with ID. Person-centred planning is an approach with demonstrated benefits in the support of older people. The focus is on the abilities, interests, values and capabilities of the person rather than the neurological and physical degenerative process of ageing especially in conditions such as dementia.

The central idea of Person Centred Planning (PCP) is to promote the empowerment, self-determination, participation and the social inclusion of each person with ID. PCP can be used to uphold the values of the UN convention of the rights of persons with disabilities.

PCP focusses primarily on the individual rather than services or resources. The person with intellectual disability is actively involved and in the centre of decision making in their life planning which takes into account the person's abilities, capacities, wishes and personal skills. This approach enables the front-line worker to see and work in a different way with a person with intellectual disability. It is an ongoing process of support through the different kinds of transitions in a life span. The tools developed to support the process of PCP are used to get to know the person very well but are only likely to be most effective when used with an attitude of understanding, openness and respect for the ageing person.

An example of a person centred approach is the use of biographical work with the person, their family and friends. By bringing together the individual's life story, often with the aid of photographs or mementos it is possible not only to better understand the values, interests, abilities, significant relationships and to see them as a unique person with a unique life story but also to rekindle memories and strengthen a sense of self and relationships in the person whose cognitive function is deteriorating. Emphasis on this biographical understanding in the daily support of the person is likely to lead to improved communication, valuing of interpersonal relationships and abilities, and enabling them to participate in more meaningful activities and to maintain skills.

Section 1: Introduction to a Person Centred Planning approach

This provides a detailed overview and through case vignettes and exercises the trainee will:

- Learn about traditional provision of services
- Learn about the history of person centred planning
- Learn about person centred approaches

- Learn about importance of PCP for handling transitions and the biographical approach

Section 2: What does Person Centred Planning mean in the support & care of Ageing people with intellectual disability

This section gives a more practical insight into how to implement a Person Centred Planning approach. Specifically the trainee will learn:

- How to use your own biography to learn about the importance of transitions in life
- How to use tools for person centred thinking and planning
- The importance of "circles of friends"/"circles of support"
- Specific aspects to consider when working with people with an intellectual disability and dementia

Section 3: Person Centred Approaches and Staff Attitudes

This section shows that whatever techniques or skills we have, our attitude towards the person with intellectual disability fundamental our approach. Three examples are given of every day practice in which this basic attitude is highlighted (for ethical reasons, the situations are presented by an actor and worker in a role play situation.)

Important attitudes are:

- Openness
- Willingness to explore, instead of judging, feelings and behaviour.
- Empathy
- Respecting a person's uniqueness
- Respecting the person's specific aspects of coping with their disability

On completion of this module the trainee should have acquired these competencies:

Transposing the person-centred thinking approach into person-centred planning

- Supporting the empowerment of service users particularly during life transitions (moving home, retirement)
- The ability to apply different person-centred tools in life planning and service planning
- The ability to bring a person-centred understanding to age-related issues, transitions, diseases, social life, retirement, physical changes.
- To reflect on their beliefs and attitudes towards an ageing person with ID and to improve the ability to regard them as a person with dreams, wishes, interests instead of a person becoming more dependent.

2.5 Module III "Social Networking and Communication for Ageing People with ID"

Karel De Vuyst & Eline Coolens
Zonnelied

The maintenance of social networks becomes increasingly difficult with age and particularly so for people with intellectual disabilities whose networks may often be reliant on other individuals, organisations or services to maintain.

Ageing people with ID:

- Tend to become more dependent on the help of others: family carers, support workers or healthcare professionals. They are likely to need more support in expressing and fulfilling their needs, preferences and choices.
- Are at risk of losing their social networks through the loss of parents / family / friends and changes in family roles. Often there are no children or grandchildren and there is a higher risk of loneliness and social isolation.

- Are at risk of deteriorating mobility which has consequences on their daily activities and again may lead to loneliness and neglect.
- Are more likely to be excluded from society with less social presence, representation and participation. There can be a lack of initiatives and / or organisations that provide access to activities and other opportunities for social inclusion. Residential provision may be limited in variety and scope, tending to be organised around congregate living rather than more individualised home settings in areas that have opportunities for social links and activities within the immediate vicinity.
- May have increasing difficulties with communication. The process of ageing is often accompanied by problems with memory, hearing, vision, speaking, comprehension, expression etc. which can also compromise pre-existing communication difficulties.

There are five sections to this module:

Section 1:
Emphasises the importance of a social network for ageing people with intellectual disability. In view of the higher risk of dependency, isolation, loss of mobility, etc. both existing social contacts and new opportunities must be nurtured. The module provides a better understanding of the concept of 'social network' and how front-line staff can promote this in the everyday life of the individual.

Sections 2/3:
These sections give advice on how to develop and improve the person's social network, to initiate, maintain and to strengthen the contacts between them and significant individuals or groups in their life. The module provides tools for exploring the social network, to actively support and develop it with particular regard to optimising mutuality in social interactions.

Section 4:
Underlines the importance of effective communication. We focus on sustaining communication in relation to the person with intellectual disability and on speaking and listening in the course of teamwork.

Section 5:
Considers problems that can be encountered in these areas and discusses potential interventions and ways forward that can be initiated by front-line staff.
After successfully completing this module the trainee should have the acquired the following competencies:

- creating a social action map for an ageing person with ID
- speaking and listening in teams
- sustaining communication in relation to the individual with ID
- reflecting on one's self in relation to one's job
- solving problems and anticipating crises
- dealing with difficulties encountered with social networks

2.6 Module IV "Emotional Regulation for Front-Line Staff"

Mag. Andreas Kocman & Univ.-Prof. Dr. Germain Weber
University of Vienna, Faculty of Psychology

The specific challenges associated with ageing and with disability suggest that professional carers will encounter a high level of potential stressors which derive from a variety of factors. These factors may be related to the characteristics of the individual with a learning disability and also to those of the carer themselves, their age, knowledge and life experiences, personal, professional coping skills and their relationship to the system in which they work.

Professional carers find supporting people who present behavioural challenges particularly stressful. In older persons with intellectual disability, the development of dementia and other age-associated mental and physical health conditions such as depression, arthritis, or cardiovascular disease, together with their treatments may also lead to the development of behaviours that are challenging: restlessness, agitation, insomnia, irritability, decreased motivation for example. Terminal illnesses and end of life care pose a significant physical and emotional

demand on carers, particularly paid carers whose main focus of support has been in enabling people to live a fulfilling lige day to day, not to be supporting someone to die at home.

The additional time needed to care for ageing people with intellectual disability due to their decreasing abilities and autonomy also directly influences the perceived stress level of carers.

It is thus not surprising that several studies show that the way in which work related emotions are handled by professional carers has a significant impact on their perception and experience of stress.

Thus, the University of Vienna has developed this training module on emotional regulation skills in the context of the AGID project. The module's aim is to provide practical guidance on how to cope better with stresses and challenges in their everyday work life:

- Reducing negative effects caused by stress
- Maintaining the highest quality of life and
- Ensuring a socially responsible behaviour towards people with intellectual disability and colleagues

Section 1 - Why use Emotional Regulation?

This provides a detailed overview of emotional regulation and specific stress factors with which one may be challenged with when working with ageing people with intellectual disability. Based on case vignettes and exercises, this section once completed should enable the trainee to develop their understanding of:

- What is emotional regulation?
- Stress factors in the work environment.
- Stress factors when caring for ageing people with intellectual disability.
- Specific aspects of caring for people with intellectual disability.

Section 2 - Stress prevention strategies for working with ageing people with intellectual disability

This addresses the consequences of stress and pressure as well as preventive coping strategies:

- Stress and burnout
- Aggression and violence
- Benefitting from resources in the care environment:
  - Co-workers
  - Problem solving behaviour
  - Relaxation techniques

Section 3 - Strategies for dealing with specific emotional challenges while working with ageing people with intellectual disability

An overview is provided of specific strategies designed to help with challenging situations in the care of ageing people with intellectual disability. In the course of several exercises, the traineed will acquire information about:

- Central life events of ageing people with intellectual disability.
- Communication skills: how to deliver bad news to people with intellectual disability.
- Death and grief when caring for people with intellectual disability.

The module is concluded by a summary of the important issues and a post-module assessment.

After successfully completing this module the trainee should have acquired the following competencies:

- Ability to reflect and systematically explore stress factors in one's own work environment
- Recognition of one's own risk of a burnout
- The ability to recognise and handle organisational or personal violence and aggression
- The ability to systematically recognise and benefit from resources available in the work environment
- Measures to ensure a social and productive exchange in a professional environment
- Knowledge of goal-orientated problem solving strategies
- The ability to use relaxation techniques
- The ability to reflecting on one's own understanding and experience of ageing and death

2.7 Module V ”Pathological Ageing in Elderly People with ID”

Marie Christine Melon & Stefano Grassi
CADIAI Cooperativa Sociale

This module looks at the most common diseases of old age, how to handle an emergency situation and how to communicate effectively with people with ID.

Section 1 - Pathological aging in ageing people with ID

This section provides an overview of some of the most common pathologies of ageing affecting people with ID, placing an emphasis on the symptoms that are slightly different from those of the general population and thus harder to detect, a difficulty that is further exacerbated by the communication problems that people with ID may have.

A series of case vignettes and exercises completes a review of the following topics:

- Ageing related diseases, grouped in three main categories: neurological and vascular problems, problems related to major organ failure and disorders of movement.
- The concept of multipathology (or comorbidity) where a number of the above disorders coexist in the same person.
- The assessment of the health of the ageing person with ID, with reference to some of the most useful validated tests to monitor the presence and the evolution of symptoms.

Section 2 - Prevention of complications

This explains some useful ways to prevent health complications related to pathological ageing. In particular:

- Useful indicators for avoiding complications of the most common health risks for aging persons with ID: swallowing disorders, malnutrition, pressure sores and falls.
- Preventive approaches in multi-pathology and assessing priorities for treatment at a team level.
- Consideration of treatment compliance, working with families and carers and improving communication in order to optimise health.

Section 3 - Management of medical emergencies

This section looks at what constitutes a medical emergency, what might require urgent intervention but not an emergency, and what are expected consequences of disease. The trainee is provided with some suggestions of how to recognise and manage these situations.

- What are the most effective strategies in communicating with emergency services when facing a life threatening situation?
- What basic information is essential in the treatment of sudden cardiac arrest and airways obstruction? Techniques employable by non-health professionals also are detailed.
- What are the most important issues regarding emotional response in facing an emergency?

The module is concluded by a summary of the important issues and a self-test.
After successfully completing this module, the trainee should have acquired the following competencies:

- Managing the care of ageing people with ID and multiple pathologies
- Adopting a preventive approach to the medical complications of multiple pathologies
- Creating a supporting environment for people with ID and dementia or depression
- Improving compliance through efficient communication with the patient and the family
- Responding effectively to medical emergencies through emotional management

2.8 Module VI “Taking Care: Complex Professional Stance”

Virginie Laurent & Patrice Morel
Les Genêts d’Or

“Caring is not just about ‘adding years to their life’, but also ‘adding life to their years”’!

The aim of this module is to offer care staff the necessary tools for reflection in order that they can implement an ethical, quality approach, which contributes to creating the conditions required to safeguard the will and rights of those in care. It promotes an holistic approach to the person and their medical and social care through the recognition of their own identity and individuality, with the greatest possible respect for their choices and intimacy. The module will also look at how to ensure safeguarding and, what is known in France as Bientraitance, in everyday work while also enabling the individual’s self-determination.

The module is divided into four main sections:

- Composed of theoretical concepts taken from clinical and cognitivist psychology.
- Supported with examples of clinical data from real-life situations.
- Completed with illustrations required to understand certain concepts.
- Illustrated with photos and vignettes showing disabled people who accompany the reader in the learning process through their story.

Section 1 - Professional Caregiving

This section is concerned with helping the trainee to analyse their own professional practice, how to avoid the trap of their own perceptions and awareness of the cognitive processes and biases that may influence how they deal with ageing people with intellectual disabilities.

Section 2 - An Appropriate Methodological Approach for Older people with Disabilities

As there is no ‘user guide’ on how to ‘take ‘care’ of older people, this section aims to promote an attitude and standards of conduct, based on a framework that sees the carers’ main task as being that of compensating for the difficulties that the individual faces in order for them to live a normal life.

The trainee will be helped to take the specific issues of intellectual disability into consideration in their use of suitable methodologies and tools for ‘real-life’situations.

Section 3 - Supporting Older people with Disabilities in their life course

Based on case vignettes and exercises the trainee will look at how to develop more personalised and participatory approaches to understanding the details of people’s lives, their needs and their expectations. Trainees are encouraged to consider ways in which they and other professionals and/or team members can ensure that the thorough assessment of, and commitment to provide for, diverse and individual needs can take priority over the needs of organisations or systems to prioritise their own and most expedient solutions and resources.

Section 4 - Bientraitance (‘Well-treatment’ or Safeguarding): A Guide to Caregiving

This concerns an approach that comes from a humanist value system and is not limited to being the opposite of ill-treatment. It involved working with the abilities and personal qualities and resources of the individual being cared for to support them in their own ‘life-project’. It is a dynamic process that also involved continual improvement of practice, always being vigilant and listening to the person, their friends and family. Whilst the approach prioritises ‘taking into account’ over ‘taking charge, it is also mindful of the need to protect vulnerable individuals from harm and abuse.

- After successfully completing this module the trainee should have acquired the following competencies:
- To be able to understand the importance and also the cautions of this model
- To recognise the significant differences in approaches that would distinguish this approach from ones that are likely to lead to harm or neglect
- To understand the use of a ‘Concerted Action’ tool in this context
- To be able to apply strategies in relation to caregiving within this conceptual framework

3. AGID - Development of Innovation

3.1 AGID's Innovative Character - Introduction to the AGID Online Portfolio Development Process

Steve Mackenzie
De Montfort University

The training platform has been delivered in 5 languages (English, French, German, Italian and Flemish) with the aim of targeting as wide an audience as possible of front-line staff working with the ageing people with intellectual disabilities, and to assure best outreach of the AGID results and outcomes.

The web-based training modules are based on evidence and the results of specific studies (empirical and practice-related) on the topics generated through the involvement of all stakeholders and within the focus groups consultation on the social and health needs of ageing people with ID (i.e. service users, self-advocates, family members, frontline staff, health professionals and policy makers).

When developing the AGID modules the primary considerations were the following:

1. The development of a stand-alone web-based e-learning application.
2. A visually appealing interface.
3. A clear navigational structure.
4. Inclusion of interactive exercises.
5. he automatic production of a certificate on successful completion of a final test.

With these considerations in mind, the development involved two distinct elements, development of the modules and development of a final test with a self-generating certificate.

Each module starts with a pre-awareness exercise to assess the trainees' knowledge on the subject and each module is divided in 3 to 4 subsections; after each of these subsections a test of the knowledge acquired is included. These tests are very interactive and take the form of role-play videos, case vignettes, open questions, Yes/No questions, interactive images etc. The online quizzes and other interactive elements are used to encourage self-assessment and development of an e-portfolio aimed at developing a range of competencies and providing an online learning space for users to reflect, collaborate and share experiences.

3.2 Evaluation of Usability of the Training Platform

CADIAI Cooperativa Sociale

The International Standards Organization (ISO) defines usability as: "The extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context" (ISO, 1998).

Evaluation of the usability of the training platform was an important stage in the process of development. It was essential to know whether the form and presentation of the training modules were actually useful and effective in enabling front-line staff to improve their knowledge and competence related to their work with ageing people with ID.

A review of the relevant literature on the concept of usability of an e-learning product was conducted. It was found that many authors in the field consider usability as essential to user satisfaction and user acceptance of a product (or system), since it can be viewed as a measure of the quality of the user's experience when interacting with a system; a difficult to use interface negatively affected learning performance in many studies. A wide number of usability evaluation methods are reported in the relevant literature, but the SUMI and SUS methods are two of the most used questionnaires in usability evaluation and research. Although not specifically designed for evaluation in this area, some studies showed that SUS and SUMI questionnaires can be effectively employed to assess usability of an e-learning software system.

It was agreed therefore to produce an ad hoc questionnaire, derived from the SUMI and SUS methods, to be tested by a sample group selected within each partner country of the project.

The AGID questionnaire

Two particular topics are examined in the questionnaire. The first deals with general aspects concerning the complexity and the usability of the graphic interface, while the second focuses on the learnability and how pleasing the system was to use.

The questionnaire needed to be able to maximise the feedback from the users, while remaining short and quick to administer and had to be capable of providing both quantitative and qualitative data about user feedback.

Along with the items on usability, others were included to collect demographic and other relevant data, such as years of work experience, educational level, general and specific computer experience and previous experience with this or similar products. These socio-demographic variables collected among the sample group were to be used to identify specific users profiles for which appropriate adjustments of the user interface might be necessary.

In order to check for technological acceptance, which can be an important confounding factor, we added the following questions after the demographic items:

- are you familiar with the use of a personal computer?
- how often do you use a personal computer?
- do you use a personal computer mainly for work, free time or both?
- did you already use an e-learning platform?

Three further questions derived from relevant literature were added at the end of the test in order to check for computer anxiety, which can be another confounding factor.
Finally, the following two open-ended questions at the end of the questionnaire were added to collect qualitative data that could be useful in identifying relevant themes for future improvements:

- what do you think is the best aspect of this system, and why?
- what do you think needs most improvement, and why?

The resulting questionnaire was translated into English, Italian, German and French language and forwarded to all the European partners of the AGID project: the instructions provided with the questionnaire stated that every single user should first complete the selected e-learning module individually, then fill in the questionnaire, paying special attention to the usability aspects of the platform, rather than on the content of the module.

Results

The final testing sample consisted of 171 users, 72% of whom where female, from seven different European countries. Of those recruited for the study, 52% were students, 26% front-line staff working with persons with ID and 9% of social care managers. Of the final sample, 48% already had worked with persons with ID.

Due to the majority being students, more than half of the samples were aged between 20 and 29 years. A large proportion of the final sample stated that thay had never had the opportunity to work with people with ID, while the remainder had worked with this group of people for a variable amount of time, ranging from more than 15 years (20 users) to less than one year (7 users). An overwhelming majority of users (95%) reported that they were already familiar with a personal computer, that they

used a personal computer more than one hour a day, both for leisure time and work.

65% of the sample reported that they already had an experience with e-learning platforms.

Akin to the global score obtained by the SUS method, we calculated an overall score by summing the points of every item of the questionnaire: out of a possible maximum score of 72, the overall mean score for the entire sample was 50.1 (70%). This result appears to indicate that the training platform is perceived as having a good usability by the tested sample.

As a further elaboration, in order to investigate the effect of different user characteristics on the perception of usability, we found it interesting to compare the mean scores of the subgroup of 'social' workers to the subgroup of 'non-social' workers (comprised mainly of students): the social workers group (82 users) attained a global score of 48.4 (67%), a slightly lower score than the toal mean, while non-social workers (89 users) achieved a mean score of 51.5 (71.5%) slightly higher than the entire sample.

We then compared three different subgroups: users over 40 years old (37 users) achieved a mean global score of 45.1 (63%), users under 40 years old (43 users) a mean global score of 51.2 (71%), while users under 30 years old (89 users) also obtained a mean global score of 51.2.

Finally, the subgroup of users that had previously already used an e-learning platform (111 users) returned a mean global score of 51.9 (72%), compared to the mean global score of 46 (64%) of the group of users that had never used an e-learning platform before.

These comparisons of the different subgroups suggest clear that a specific user profile, namely a user that is under 30 years old, is still a student and already had an experience with e-learning platform appears to find the module platform more usable and easy, thus is probably slightly more advantaged in benefitting from the system. Conversely, users over 40 years old, working in the social field and that never used an e-learning platform may find the platform slightly less usable than the average of the entire sample.

These were largely predicted and this gives some indication that the instrument used is sensitive enough to detect them.

A difference in the mean global usability score was found also between persons that already had an experience with e-learning platforms and persons who didn't, though this difference is not as great as might have been expected: this finding may indicate that the platform revealed itself to be as usable and easy, independently of the previous experience of the user.

From a further examination of the individual items, it appears that younger users and users who had previous experience with an e-learning platform need less training and support in going through the modules; moreover, in looking at the usefulness of the provided information and prompts, users over 40 years old declared that they needed assistance more than the users aged less than 30 years who found prompts more helpful. Additionally, users that never used an e-learning platform before stated that they had to keep looking back at the guides more than users that had a previous e-learning experience.

Users over 40 years old, social workers, and with no previous experience with an e-learning platform found it more difficult to comprehend the information presented, compared to the other subgroups, and they were more anxious and less confident in their ability to learn how to use the platform. Nonetheless, the users above 40 years old found the platform more mentally stimulating than the users aged less than 30, indicating that they may exhibit more commitment to the e-learning platform, thus overcoming some of the difficulties found.

All the subgroups studied found the platform attractive, largely due to the multimedia content of the modules (images, interactive exercises, videos).

In addition to the many positive comments received, there were some criticisms that are expected to be addressed in the final adjustment phase of the modules. One of the most cited was the readability of the font, particularly the font size and colour in respect to the background. Some users suggested that a way to resolve this issue could be through adding the facility to enlarge or zoom the page. Nonetheless, the attractiveness of the platform seemed to be acknowledged by a large majority of the users and this is particularly important since, in the literature on usability it is widely considered as a significant factor.

External Evaluation Structure

PROJECT OBJECTIVE	EVALUATION OBJECT	EVALUATION REFERENCE AND PROCEDURE
1. To improve the quality of life of people with ID by increasing the knowledge and competency of frontline staff and professionals	1.A Validity of QoL models and assessment tool and procedures	Literature (standardized procedure, validation)
	1.B Indicators of staff's knowledge and competency improvement	Indicators' check
2. To conduct a mapping of policy, needs and services for older people with ID based on the needs analysis	Policies and services mapping procedure and tool	Proof of sensitivity and validity
	Need analysis procedure	Proof of sensitivity and validity
3. Involve people with intellectual disabilities and their families in the formulation and development of the training	Level of involvement	Meeting reports and documents produced by people with ID and/or their parents or relatives
4. To involve professionals and frontline staff from a range of service agencies in the formulation and development of the training	Level of involvement	Meeting reports and documents produced by staff members or service agents
5. To develop training module using the Delphi consensus method across partner countries	Consistency of training module contents with current scientific knowledge on the specific topic, training need assessment, and indication from people with ID and their relatives	Consistency with Delphi consensus method. Literature (current scientific main topics). Reliability between training module contents and documents produced by people with ID, relatives, staff members, and service agents.
6. To implement the training module using innovative web based format	Actual innovation level. Structure, aspect, interactivity and comprehensiveness of the web based format	Other training format
7. To evaluate the training module(s) and its impact in proving personalized care for older people with ID	Adequacy of evaluation procedure and tools (i.e. care planning and care method of trained staffs)	Similar evaluation procedure and tools
8. To disseminate the training module(s), its currency and impact in improving the quality of life of people with ID across European countries	Actual level, method and procedure of dissemination	Dissemination method and procedure of similar projects number of congress communication, publication, service endorsement, web feedback
9. To reflect the UN-Convention on the Rights of People with disabilities in all the steps of the project.	Actual step by step consistency with the UN Convention on Rights of PwD	UN Convention on Rights of PwD

3.3 External Evaluation of AGID Objectives and Achievements

The AGID project included an external evaluation aimed at providing an independent monitoring of:

1. The impact of the training modules in the 6 countries and of the whole e-learning platform.
2. Evaluation of the project products (newsletter, website, training modules)
3. Ongoing 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 details of the evaluation will be published elsewhere but broadly speaking, the evaluation highlighted the following issues:

- The importance of providing some main theoretical reference for understanding measures of quality of life, their application and measurement.
- A structured assessment of staff knowledge and competency improvement could be made more evident and reliable.
- The need for a summary of the recent literature on policies and services, particularly in Europe (v.i.)
- The development of the training modules was based very much on the co-production approach, focus groups consultations determining the 'syllabus'. Other issues that are addressed clearly in research and other literature in this field. may require emphasis in future developments:
  - generic quality of life conceptual models and assessment tools for ageing people with ID
  - family quality of life
  - problem behaviour
  - specific cognitive functioning
  - the association between mental and physical disorders and multi-morbidity
  - Structured indicators of effectiveness of the care planning and intervention could be used to interpret impact of the training

3.4 Final Dissemination Conference in Vienna 25.02.2014

"Co-production of Service and Knowledge Transfer"

The Final Dissemination Conference of the AGID project took place in Vienna on the 25th of February. The presentation of the training platform on Ageing and Intellectual Disability explored many classic and interactive methods of knowledge transfer. The AGID achievements and outcomes have been presented through: key note speakers; roundtable; direct online testing of the training platform; and world café setting focused on co-production of services for disabled. The conference have been simultaneously interpreted in English, French, German and Italian, as also in easy to read by two buddies and a graphic facilitator. All stakeholders have been represented at the Conference in accordance with AGID methodology (persons with ID, their families, front-line staff, handicap professionals and policy makers) which included all the stakeholders within the development of the project as also within the delivery of results. The event was conceived with the idea to present and explore new innovative interactive methods of knowledge production and knowledge transfer.

Users Involvement:

Harald Ellbogen, Self-Advocate, Lebenshilfe Austria

I wish that ageing people with learning disablities are taken seriously. Older people with learning disabilities should be able to decide for themselves and choose HOW and WHERE they want to live.

It is also important that health and social care staff acquires better knowledge of the needs of older people *with learning difficulties and you should also provide us with information on treatments and medicines in easy to read.*

Policy makers:

Maria Cristina Cocchi - Director of Social Heath-Bologna District
The increase and diversification of needs requires special attention to the personalization and quality of interventions, as well as answers truly flexible through different pathways of individualized care; the sustainability of this line of action requires a strong innovation of our supply structure.

Academics and researchers:

Maria Bruckmüller - Honorary President of Lebenhilfe Austria
People with disabilities experience ageing nowadays and improvement of their living conditions is a new experience and we must make sure that is a positive one.

Germain Weber - Dean Faculty Psychology University of Vienna
We must develop education programs, training, and information provision on ageing and disability issues (knowledge, attitudes and values), including human rights and citizenship perspective for staff and other careers.

Professionals in the Field of Disability:

Raymond Ceccotto - General Director of A.P.E.M.H./ President of ARFIE
Capacity building of the workforce in delivering personalized care for older people with ID shall be priority of the decision makers and for public financing

Patrice Morel - Director Les Genêts d'Or
We need to be proactive in anticipating and developing specific support for ageing people with disabilities who live with ageing family careers.

AGID - Dissemination Conference 03.04.2014

"Quality Service in an Ageing Society - the Importance of Life Long Learning"

In collaboration with ANEFORE (Luxembourg Agency for Education and Culture) and hosted by the European Commission, AGID's second dissemination conference took place on the 3rd April 2014 in Luxembourg. A.P.E.M.H. Foundation together with RBS - Center fir Altersfroen organised this study day on what quality service provision to disabled in an ageing society means and the positive impact of Life Long Learning on quality service provision. The objective of the conference was to disseminate AGID outcomes and to discuss and identify with the different stakeholders common quality criteria for services to aging people with disabilities.

Professor Johann Behrens
draw the attention to a very important consideration: saying that health professionals tend to think they know what is right when treating the user- opposite to self-determination of the user as foreseen by UN CRPD!

Roland Anen - A.P.E.M.H. President
We must take into account the individual needs of the person, since self-determination of the user has demonstrated to be the most important milestone into achieving quality of support.

Georges Bingen - host of AGID conference at the European Commission in Luxembourg
talked about how we must provide Active Ageing opportunities for people with ID and how active ageing is connected with EU citizenships rights agenda.

Daniela Janeva - AGID Project Coordination reminded people that
Active ageing "is the process of optimizing opportunities for health, participation and security in order to enhance quality of life as people age". It is important to note that the word "active" does not just refer to physical activity, but to participation in relevant social, spiritual, economic, cultural and civic affairs as well. Therefore a disability that prevents engagement in physical activity is not necessarily a barrier to active ageing, as that person could still be active in other ways within their community.

3.5 Co-production in Public Services

Professor Raghu Raghavan
De Montfort University, Leicester

The past three decades have seen a major shift from a "medical" to a social model of intellectual disability where the person with a disability is seen as an ordinary citizen with rights of equal access to and use of ordinary community services.
In the United Kingdom for example, the programme of closure of long-stay hospitals and campus-based institutions has led to the expansion of wide ranging patterns of services in the voluntary and independent sectors. During this period, the service user and disability rights movements have promoted the idea of people who use services as active participants with innate resources, rather than passive dependents with needs. The associated move towards 'personalisation' in adult social care services can be seen as a continued response to this need for choice and control and has resulted in such developments as direct payments and personal budgets.
In England, a major policy initiative, Valuing People (Department of Health, 2001), presented the government's strategy for improving the lives of people with intellectual disabilities and their families. The strategy was based on the recognition of their rights as citizens, the need to support social inclusion, to give choice in daily lives and to provide opportunities to achieve independence.

Valuing People included recognition of the importance of the social context in the lives of people with intellectual disabilities, for example, through its concern with social inclusion. Its interpretation in practice has been an individualistic one based on the principles of person-centred planning (PCP), an approach encouraged across a range of health, social care and education settings (Small et al 2013). The aims of PCP are both to personalise the planning experience and to influence strategic planning (Felce, 2004). However, a systematic review of the literature (Claes et al., 2010) concluded that there was little evidence that PCP resulted in increased accessibility for service users and little evidence of its impacting on structural problems of service delivery (Cambridge and Carnaby, 2005). Furthermore, there is no clear evidence of a link between PCP and outcomes for service users (Black et al., 2010; Robertson et al., 2007).

The Social Care Institute for Excellence (SCIE) report on Co-production highlights that that public services need to work with the people who use services (SCIE 2013). This report argues that the failure to listen to the voices of people who use services and carers has been a key theme in all the high-profile scandals in health and social care in recent years. In England, recent enquires into the abuse and neglect of people who use services have highlighted the need for service providers to develop more equal relationships with people who use services and carers. In this context co-production provides the concept and the framework to develop these more meaningful relationships for service development with users and carers playing equal role with commissioners and professionals.

What is Co-production?

The literature suggests that there is no single definition of co-production. The concept represents a set of values and principles which have emerged over a period of time having been introduced in the 1970s by Elinor Ostrom (Ostrom 1072). The New Economics Foundation described co-production as "delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours".

The definition included in the Department of Health's Personalisation Communications Toolkit was fully co-produced with service users and carers, with the following wording being agreed:

"Co-production is when you as an individual influence the support and services you receive, or when groups of people get together to influence the way that services are designed, commissioned and delivered."

According to Needham (2009) co-production refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else. It emphasises that the people who use services have assets which can help to improve those services, rather than simply needs which must be met. These assets are not usually financial, but rather are the skills, expertise and mutual support that service users can contribute to effective public services.

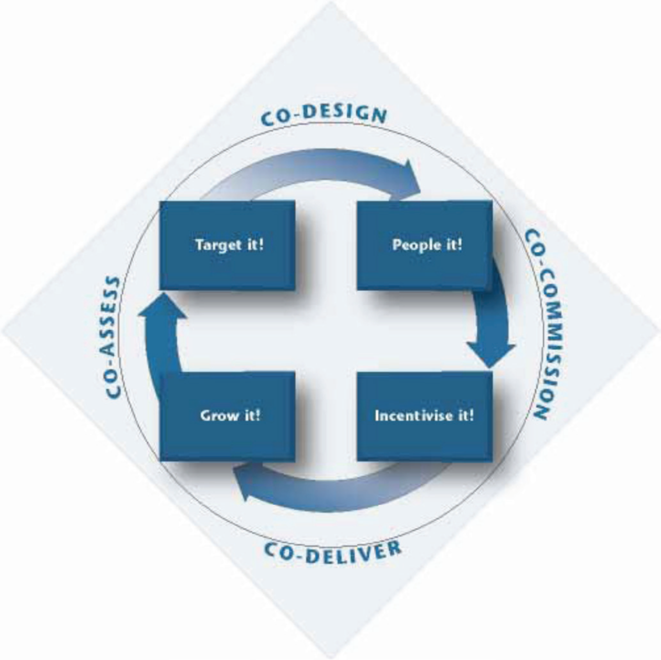
The Department of Health (2010) in England suggest that within the co-production umbrella we can find elements of engagement, participation, choice and control, and involvement.

Organisations seeking to build co-production into their organisational frameworks need to work with staff, users and carers to take the first step to define what co-production means for their organisation:

The key features of co-production are:

- defining people who use services as assets with skills
- breaking down the barriers between people who use services and professionals
- building on people's existing capabilities
- including reciprocity (where people get something back for having done something for others) and mutuality (people working together to achieve their shared interests)
- working with peer and personal support networks alongside professional networks
- facilitating services by helping organisations to become agents for change rather than just being service providers.

Co- production consist of co-design, including planning of services, co-decision making in the allocation of resources, co-delivery of services, including the role of volunteers in providing the service, and co-evaluation of the service. Hence this model is a fully inclusive process that transforms the way we look at the planning and delivery of services. In this model, service users, carers, commissioners, professionals and other service agencies work in equal partnership in developing services. Hence co-production is about transformation of services and the emphasis is on the involvement and participation towards people who use services and carers having an equal, more meaningful and more powerful role in services.



Services for people with intellectual disabilities of all ages can be improved using the co-production model, as this will be a fully inclusive process and will transform the way we go about the planning and delivery of services for vulnerable people in our society.

4. Lifelong Learning in Services for People with Disabilities

4.1 Lifelong Learning and Quality in Social Service Provision

Daniela Janeva
AGID Project Coordinator

We have witnessed an important paradigm shift in recent years from a 'medical' model of disability toward a social and human rights model that seeks achievement of full citizenship and inclusion of the disabled and implies a recognition that the environment is disabling and not the impairment per se.

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 in order that the services can reflect their needs.

The involvement of service users and all relevant stakeholders in the design, delivery and evaluation of social services for the disabled are central to service quality. The Structural Funds and the Lifelong Learning educational program of the European Union can strongly support (public financing) 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.

Building workforce capacity and the development of the skills, competences and knowledge of all stakeholders have a positive impact on the quality of the services provided. Ratification of the United Nations Convention on the Rights of Persons with Disabilities requires the EU and member states to work to provide ***"improve access to quality, affordable health care services, which make the best use of available resources"*** for people with disabilities.

The education and culture program of the European Union should strongly encourage innovative research and knowledge transfer programmes in health and social needs of ageing people with intellectual disability that would underpin and drive the development of a more universal person-centred and holistic approach to supporting people with a disability in Europe. Providing personal professional and vocational training, non-formal and informal learning to people with ID and those who support them, are crucial in their empowerment and in the reduction of poverty and social exclusion of the disabled.

4.1 Recommendations for Development of Public Policies on Service Provision to Ageing People with ID

Dr Roger Banks & Professor Raghu Raghavan

A document from the United Nations on World Population Ageing (2009) states that: "As the proportion of the world's population in the older ages continues to increase, the need for improved information and analysis of demographic ageing increases. Knowledge is essential to assist policy makers define, formulate and evaluate goals and programmes and to raise public awareness and support for needed policy changes". See World Population Ageing (Working Paper), UN (2009) for more details.

Why does an ageing population mean we need to make changes to policy? As we have already covered in the first section, our needs change as we age. Policy should reflect this change to meet the needs of a growing number of older people. This will require revisions to be made to areas such as:

- Healthcare
- Housing
- Pensions
- Access to care, including residential care homes
- Employment & Retirement

The United Nations have been called upon to act on some of the human rights challenges faced by older people. The UN working group on the rights of older people suggests that the right to the highest attainable standard of physical and mental health of older persons is at the core of human rights concerns. Other areas include:

- **Age discrimination:** identified as one of the most frequent challenges faced by older persons around the world.
- **Multiple discrimination:** as a combination of different grounds of discrimination. This is particularly the case for older women, and will apply to older people with intellectual disability.
- **Ageism and prejudice:** was also recognised as having an impact on various human rights.
- **Violence and abuse** against older persons was also a key issue.
- **Access to justice:** the need to create measures to support the exercise of legal capacity by older persons related, for instance, to health treatment, property and inheritance.
- **The right to social protection:** the adequate protection that older persons deserve.[7]

Disability, both physical and mental, will be an increasing feature within older people's policy and practice as improvements in health and social care lead to increased life-spans for people with disabilities. This presents a relatively new challenge, and so current policy is inadequate. However, there are recent policies which aim to tackle some of these issues. For example in the UK:

- **In July 2013, the Department of Health (England) committed funding to build 3544 affordable new homes for older or disabled people.** These homes are to be designed to help these people live independently, for example by having adapted bathrooms, handrails, wheelchair accessible cupboards, and few or no stairs.
- **In June 2012 the UK government published a white paper called "Caring for our future"[8], which proposes changes to the care and support system such as:**

  - Requiring local authorities to provide support in the early stages of developing issues, in order to promote independence and possibly delay or reduce the need for a critical intervention.
  - Standardising the eligibility criteria for support across the country, as opposed to it varying between local authorities.
  - Better support for carers, such as those eligible receiving their own personal budget to spend on care as they see fit.
  - New national minimum training standards for care and support workers, with an emphasis on dignity and respect.

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[7] UN Progress and Challenge for the protection of the Rights of older persons: An International Perspective, UN (2011)

[8] http://caringforourfuture.dh.gov.uk/

If these proposed changes and recommendations are followed, quality of life for older people with intellectual disabilities will improve in a number of ways:

- The emphasis on supporting independent living should see more people with intellectual disabilities being able to spend their old age in their own homes.
- Better support for informal carers should lead to higher quality care.
- Better training for care and support workers should lead to higher quality care.
- A person-centred, human rights based approach should lead to better treatment for, and less discrimination of, older people with intellectual disabilities.
- Specific health promotion/disease prevention initiatives should lead to better health for older people with intellectual disabilities.

The Graz Declaration was produced in 2006 by (and applicable to) a number of stakeholders in the disability and ageing sectors from across Europe, including older people, people with disabilities, carers, academics and policy makers. It states that policies related to ageing and to disability had not considered the needs of people with intellectual disabilities and made a number of recommendations:

- To develop specific programmes of health promotion/ disease prevention for ageing people with disabilities.
- To ensure that national legislation promotes and recognises supported information and decision making for ageing people with disabilities.
- To take a human rights and person-centred approach to enabling ageing people with disabilities to live and participate in their community.
- To develop formal education programmes, 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.
- To be proactive in anticipating and developing specific support for ageing people with disabilities who live with ageing family carers.

The World Health Organisation outline a number of practical ways to promote healthy ageing in the general population:

- Increasing healthy life year expectancy by promoting health and tackling the causes of ill health, focusing particularly on implementing lifestyle change during early old age (50+ years).
- Creating age friendly environments by addressing transport, infrastructure, pollution, housing, public spaces and services.
- Improving health and social care services by better coordinating care, anticipating gaps in the healthcare workforce, and improving sustainability of public funding.

Other suggestions include:

- Increasing retirement age and labour market participation rates to 75%.
- Creating a single European market for health-related products and services.

The WHO report on Ageing and Intellectual Disabilities (2000) highlights six outcomes that services can work towards to promote healthy ageing amongst their service users:

- Practical, leisure or life enhancing skills (i.e. making choices between alternative activities and allowing person to access community opportunities for work or retirement).
- Improved or maintained dietary and general health status that prevents physical health factors from hindering typical activity.
- A varied rhythm of life (i.e. involving preferred activities);
- Recognition that challenge and productivity must continue throughout old age.
- An increased and well-established social network.
- And participation on a regular basis in the general life of the community, with friends or acquaintances of one's preference.

Conclusions: Achievements and Recommendations

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The AGID training platform on Ageing and Disability should be able to achieve great outreach and to target a large number of people working in the care and support of people with ID due to the breadth of languages in which the training material is available (English, French, German, Italian and Flemish). The platform[9] will also remain active beyond the lifetime of the project permitting wider dissemination and use.

It is expected that the outcomes of such accessible training 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.

AGID supports the following actions:

1. Inclusion and person-centred care for elderly and ageing people with intellectual disabilities is essential within service provision in order to meet the aspirations for a SOCIAL EUROPE
2. Capacity building of the workforce in delivering personalised care for older people with ID should be a priority for decision makers and for public financing
3. Implementation of the UN-Convention on the Rights of Persons with Disabilities is essential in order to achieve equal rights and opportunities for all
4. EU and Member States must enable 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-centred approach to enabling ageing people with disabilities to live and participate in their community.
6. Development of formal education programmes, 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. Of primary importance: the need to be proactive in anticipating and developing specific support for ageing people with disabilities who live with ageing family carers.
8. The acceptance and usability of the AGID training platform should lead to the development of similar training programmes on a range of topics for carers and professionals supporting people with ID.

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[9] The AGID e-training platform is composed by 30 modules (6 modules in 5 languages) also useful for careers of Elderly people in general within daycare and home settings.

The training, regulation and support of a capable workforce has been repeatedly addressed and emphasized throughout this project. Mobility of professionals and care workers within Europe is an important issue in this regard and a number of EU initiatives are addressing this. Most significant perhaps, in the context of this project is the recommendation of the European Parliament and the Council for the establishment of a European Credit Transfer System for vocational education and training (ECVET) which was officially adopted in May 2009. The adoption and implementation of ECVET in the participating countries is voluntary and it aims to facilitate the recognition, validation and accumulation of learning outcomes of individuals aiming to acquire a qualification which:

- improves the general understanding of learning outcomes
- increases transparency, cross-border citizens-mobility between and within Member countries
- fosters learners and labour mobility and portability of qualifications in a borderless area of lifelong learning
- supports flexibility of programmes and pathways to achieve qualifications, enhancing the opportunities for lifelong learning
- makes it easier to recognise the learning-including non-formal learning-achieved by learners in other contexts

By 2012 countries were expected to have created the necessary conditions and initiated measures for gradual implementation of ECVET to vocational qualifications at all levels of the European Qualifications Framework. The European Commission is expected to report in 2014 to the European Parliament and the Council on the results of testing and assessment of actions taken at Member State level.

The European Commission pledges to support the introduction of ECVET by:

- Developing user guidelines and further instruments
- Adapting the Europass documents
- Fostering a European ECVET network
- Evaluating, monitoring and accompanying the results and tests of ECVET and if necessary evaluating and adapting the ECVET recommendation in cooperation with the Member States

It is clear that the AGID project and its outcomes could provide useful support and an indication of future direction and investment to this initiative.

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