

TRIADE

TRAINING FOR INCLUSION OF AGEING PEOPLE WITH DISABILITIES THROUGH EXCHANGE

Newsletter #5 - September 2017



Editorial - Lessons learned

Johan Warnez - den achtkanter vzw, Kortrijk (B)- project coordinator

10 enthusiastic European organizations established a *learning network* to share organizational and educational policies and practices and to define critical factors of success to support ageing people with a disability in an inclusive way. All members of the partnership – unconditionally – believed that community based support and opportunities for living in an inclusive society with equal rights for everyone, contribute to the wellbeing of all citizens. At the very beginning of the project period, some partners already were implementing inclusive practices successfully, while others were defining new policies and/or strategic goals or were setting the first moves to implement a new policy. Some partners are closely linked to research, education, organization development and support. Small organizations as well as organizations covering bigger regions were involved. Services for the elderly, services supporting people with a disability and organizations active in both fields are part of the TRIADE group.

Supported by the European Commission (within the Erasmus+-framework), the partnership could work together intensively for 26 months, from September 2015 on. International meetings, always focusing on a specific item of inclusive support of ageing people with a disability, created opportunities for the participants to learn from each other by active reflecting on innovative or challenging local, regional or national policies and practices. Local Expert Groups – established (at least one) in each country with representatives of other organizations active within the same or different field, universities, public bodies, ... – served as an extension of the mere partnership, by giving additional feedback on the practices and their significance for local or national challenges and by giving input to recommendations for policy makers on all levels and for education.

The TRIADE project was based on a problem definition that refers to the growing number of ageing people, also ageing people with disabilities; this group of citizens, not explicitly addressed in European programs or actions, are – often – staying in an institutional living context or are supported – exclusively – by professional employees of services active in the disability field. Also, service providers, organisations and the whole society are expected to make

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Editorial (cont.)

Johan Warnez

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the transition to effective community based services – accessible for all. This is part of the positive evolution towards an inclusive society and the paradigm shift towards a social model of support, full and active citizenship, etc. This has a consequence for services and other stakeholders, especially education: the range of professions and roles, skills and attitudes required will be different before, during and after this transition.

As the project was developing, a limited number of themes were running as common threads through the reflections on the practices, independent the specific context of these practices. It was surprising – or not!? – to see that these themes are not exclusive themes, not solely linked to people with a disability, but being meaningful for all citizens.

* The (ageing) person (with a disability) is in the middle of the picture: his/her **Quality of Life** as perceived by the ageing person *himself* (his wellbeing, autonomy, self direction, social inclusion...) is what matters. QOL is a larger concept than the mere inclusion concept, that – according to us – is referring to a characteristic of society. Support needs, related to the disability or the impairments and the personal preferences and (universal) rights, need a holistic framework to realize the best support for people that contributes to QOL and the full execution of their rights.

*The **'new' professional** – giving an answer to the challenges and participating to the new approach - needs to be empowered, trained,... to execute new roles. Relevant conditions and competences are related to a mindset with positive perceptions on the ageing people and with attitudes that give the power to the ageing person, to medical/health related skills and social inclusive skills, to work together with other fields and doing so to coordinate, facilitate, etc.. The actual staff is (often) not ready to fulfil this new & additional role.

* Family care givers and volunteers, need to be valorised and supported, as **informal care** is a key item in a community based approach: bringing back support to the community and the social network of the person, as far as there is no need for impairment or disability-specific care or support. Society benefits from this in an economic way, the ageing person benefits on the level of his wellbeing.

* Throughout this themes, the societal perception on ageing, ageing people, and people with disabilities – both health and economics related – has a huge impact on policies and education: why doing efforts and allocate financial means to something that has a negative connotation? Strategies to change these **perceptions** need to be combined with forms of valorisation of working with ageing people and attractiveness of the educational curricula.

Many reflections and ideas were generated during the discussions on the presented practices. The 4 themes, together with a set of reflections and starting points for 'work to do' are summarized in the final report, that will be presented during a final meeting in Kortrijk later this year. In this newsletter, partners of the consortium are invited to share reflections with the reader as an introduction on an overview of the main ideas. *The learning network learned that the focus needs to be on the **client's focus and quality of life**, that the challenge is **labeling and negative perceptions**, ageism being one consequence—relevant for our project, and that our mission is to work towards **'new' professionals**.*



Information on TRIADE is available on **Facebook** (<https://www.facebook.com/triadeproject/>)

Linkedin (Triade Erasmus+ community). A leaflet with a description of the project is available in each participating country (see list of partners p.14)

3 statements regarding Quality of Life of ageing people with disabilities

Tinneke Schiettecat, Jorrit Campens & Ilse Goethals - University college *HoGent*, Ghent



The last decades witnessed a growing attention for the ageing process of people with lifelong disabilities (Walker & Walker, 1998). In different policy and care settings, as well as in the Triade-project, this development has provoked debates about the resources that are necessary to best ensure their quality of life. In what follows, we focus on some statements frequently heard in this context and briefly discuss them based on international research, our research experiences at the Expertise Center on Quality of Life (University College Ghent) and on recommendations issued during the Triade-meetings.

STATEMENT #1: “This person’s needs are not severe enough to receive our support.”

As Welfare States want to distribute scarce public resources as effective and efficient as possible, it could be argued that the concern to deliver services to those most in need of support in order to contribute to their quality of life is a legitimate one. At the same time, however, this issue raises two important problems.

Firstly, the question remains what can be identified as ‘needs’? When are someone’s needs considered severe enough? And by whom? The response to these matters has increasingly been standardized, as embodied by rational-technical scales and decision-making tools (Söderberg et al., 2015). In Belgium, for example, the so-called ‘Katz-scale’ has been developed to attribute people a score according to their level of independence on areas such as washing, clothing, moving, continence and eating. What is acknowledged as ‘needs’ is consequently defined beforehand, external to the people themselves and without taking into account their perspectives, nor the contexts they are living in. Often, it also results in a strict focus on measurable needs, such as mere physical or practical concerns, with the risk of disregarding the perhaps equally important social, emotional and intellectual issues as well as the interaction between them.

A second problem, that is intertwined with the first one, is that the public funding of social services is commonly linked to the outcome of the established scales. This could entail that a person who can – pure physically speaking – eat, wash and clothe himself or walk around the house gets a very low score on the scale and subsequently generates less funding for the care setting. The fact that he, for example, has lost the intent or totally forgets to eat, wash and clothe himself without the support of others cannot be taken into account. As a result, he is often left excluded from the resources that are – from other points of view – definitely needed to safeguard his quality of life. Hence, we state that if Welfare States truly aim to promote human rights, social justice and contribute to every citizen’s quality of life, they should find ways to embrace the inherent complexity of people’s welfare concerns and to continuously (re) negotiate various interpretations of needs and support.

STATEMENT #2: “Ageing people with intellectual disabilities do not belong here!”

The second statement should be viewed in light of the current debates about which service (i.e. services for people with intellectual disabilities (ID) or aged care facilities) is most appropriate and responsible to address the needs of ageing people with ID. Although most services for people with disabilities committed themselves to working with people till the end of their lives, today’s practices of relocating older residents with ID to aged care facilities (nursing homes) is clearly challenging this principle of ‘ageing in place’. Reasons for moving older people from ID services to residential aged care is sometimes prompted by structural (e.g. “no longer set up for that type of care”) (Thompson, Ryrie & Wright, 2004) or medical care (e.g. “need for more intensive medical care”) issues (Webber, Bower & Bigby, 2014). In residential aged care, on the other hand, caregivers are more reluctant to uptake the care for people with ID based on social issues, next to insufficient knowledge and communication skills to adequately address ID support needs (Thompson, 2002). While in both service systems the decision for relocating a resident is considered to be ‘in the best interest of the client’ it not necessarily starts from the desires and preferences of the resident. We argue that the question as to where ageing people with ID belong, cannot be answered by debating services responsibilities or appropriateness, but should start from a person’s human rights and personal choice. As agreed by all Triade members, it is the ageing person himself who should decide where he would like to live. In this context, the ageing-in-place-principle is defined as

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Statements on QOL (cont.)

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'free choice' which is the main particle of a good quality of life and actually transcends earlier debates. In different contexts, however, the question remains whether and how the contemporary discourse on 'free choice' is also realized in practice. In this regard, the Triade members believe that services should always keep investing in new ways to 1. help ageing people with ID to express these needs and aspirations, 2. support them in growing old where and how they prefer, and 3. eventually enhance their quality of life.

STATEMENT #3: "It's hard to tell what quality of life could entail for people with disabilities"

As protected by international human rights laws, all people – including older people with disabilities – have the right to make choices and to express their preferences (Brown & Brown, 2009; Rubin et al., 2016). In this context, there exists a growing attention for quality of life-assessments in order to increase our understanding about what clients consider important in their lives and, as such, contribute to the development of individualized support plans (Logsdon et al., 2002; Tripathi & Tripathi, 2013). Although several quality of life-measures have been developed – often incorporating both subjective and objective elements of quality of life – it seems important to question to what extent they recognize the uniqueness of individuals. Do quality of life-tools adequately represent the individual's perspective, as they are often composed by preselected domains or indicators? Are these domains or indicators relevant for each individual (Carr & Higginson, 2001; Ventegodt et al., 2003)? These questions have also been raised during one of the Triade-meetings. Although some participants stress the value of assessment tools that can measure the quality of life of older people with disabilities, others express their concern that these tools may risk to reduce the complex and dynamic issue of quality of life to a more static and technical one that can be scored according to fixed categories that are defined beforehand. Therefore, they rather suggest more space for continuous processes of negotiation, dialogue and reflection. At the same time, however, it is mentioned that the construction of an instrument with certain indicators – not necessarily scores – may be vital as a starting point to consider what happens or should happen in practice. In this respect, some Triade-members argue that the required process of questioning, deconstructing and reconstructing interventions may never occur without certain tools for reflection. Nonetheless, we should remain cautious about how and to which end these instruments are used in practice.

Common statements as the ones we discussed here are clearly not unproblematic. At the same time, we consider it crucial not to ignore them, but to keep on debating their underlying concerns from the perspectives of human rights and quality of life for all. This way we can open up possibilities to realize the unexpected.

LITERATURE

- Brown & Brown (2009) Choice as an aspect of quality of life for people with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 11-18.
- Carr, A.J. & Higginson, I.J. (2001) Are quality of life measures patient centred? *BMJ*, 322, 1357-1360.
- Logsdon, R., Gibbons, L., McCurry, S. & Teri, L. (2002): Assessing Quality of Life in Older Adults With Cognitive Impairment. *Psychosomatic Medicine*, 64, 510-519.
- Rubin, I., Merrick, J., Greydanus, D. & Patel, D. (2016) Health care for people with intellectual and developmental disabilities across the lifespan. Switzerland: Springer International Publishing AG Switzerland.
- Söderberg, M., Stahl, A., & Emilsson, U. M. (2015). How the care managers handle the process when older people consider relocation to a residential home. *British Journal of Social Work*, 45, pp. 2423-2440.
- Thompson, D. (2002). Misplaced and forgotten. *Foundation for people with Learning Disabilities*.
- Thompson, D., Ryrrie, I, Wright, S. (2004). People with Intellectual Disabilities Living in Generic Residential Services for Older People in the UK. *Journal of Applied Research in Intellectual Disabilities*, 17, 101-108.
- Tripathi, S.M. & Tripathi, R.K. (2013). Quality of Life of Cognitively Impaired Older Adults Living in Community. *International Journal of Science and Research*, 4(3), 331-335.
- Ventegodt, S., Hilden, J. & Merrick, J. (2003). Measurement of Quality of Life I. A Methodological Framework. *The Scientific World Journal*, 3, 950-961.
- Walker, A., & Walker, C. (1998). Normalisation and 'normal' ageing: The social construction of dependency among older people with learning difficulties. *Disability & Society*, 13(1), pp. 125-142.
- Webber, R., Bowers, B. & Bigby, C. (2014). Residential aged care for people with intellectual disability: A matter of perspective. *Australasian Journal on Ageing*, 33(4), 36-40.

Approaches and... (new) professional competences

Jose Gil, Maria Sorzano & Jose Campillo - IVASS Valencia (SP), Daniela Moro—Irecoop It), Sara Morgan & Marie Skoghill—Eskilstuna (Sw)



Ageing people with intellectual disabilities have the same rights and may have the same needs and competences (or lack of them) as their non-disabled counterparts. Therefore, both groups should be equally treated with the same theoretical and practical approaches. We are going to explain in this article three of the most important ones: The inclusive approach, the self-determination approach, and the networking approach.

One measure that can be taken to guarantee the client's interests and rights is applying the "*Inclusive Approach*". According to this, ageing people with intellectual disabilities must be supported in the place where they wish to get older, leaving the traditional elderly services only as a last resource.

Furthermore, public health, biomedical, social and behavioral research have provided new evidence to improve prevention and treatments for our target group. According to it, services and professionals should be an existential guarantee for people with disabilities. This means that at the center of the inclusion process there would be no pieces of individual but the individual itself.

Regarding the "*self-determination approach*", this is a process based on the principle of giving to ageing people with disabilities the option to take an active part in choices and decisions concerning their lives. It is not just about paying attention to the person's tastes and preferences, but above all enabling clients to increase their awareness and positioning capacities within reality. Thus, a socio-educational work to develop a client's life project fulfils the wishes of autonomy. Unfortunately, they, and their informal care givers, are often not involved in their decision-making processes. In addition, ageing people with disabilities may lack enough capacity or willingness to express care preferences and needs. From the point of view of the self-determination approach, it is crucial for the professionals to work with their clients and family (client perspective).

The third of the approaches is linked to the clients and entity stakeholders. According to it, professionals also need to promote "*networking*" to improve social inclusion processes and to build bridges between services and companies, developing significant relationships with local stakeholders in order to offer inclusive opportunities to ageing people with disabilities. It must be recognized that the relationship with the service user is temporary, with the logic that people should be able to live as much as possible within the community. This means supporting the development of the ability to "learn to motivate" people with disabilities and seize any opportunity to train/develop cognitive skills and to experience "risks" in order to increase their potential autonomy, giving the opportunity to the clients to experience authentic social roles.

These three approaches should be understood as a holistic one in which health and social welfare are equally considered. All of this will require a huge effort to improve not only the professional's competences, but also the service's organization and culture, establishing in the organizations an ongoing process of change.

At the organizational level, considerable improvements will be needed related to the reliability of the service, personalization of the attention, the answers to the clients' needs, the relationship with the professionals, the lifelong learning approach. In addition cooperation across sectors and between stakeholders is required.

At professional level, the actions should be oriented to improve empathy and authenticity of the treatment; knowledge about communication; adaptation to different situations. Cognitive challenges and the individuals' needs and conditions will have to be addressed.

Professionals also need to recognize and support the different phases of the life cycle of a person with disabilities, with particular attention to the adult and elderly periods. In this context, a key issue is the prompt recognition of the social role of people with disabilities. This is the ability to express an active position and participate in the context where they live in.

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Approaches and... (new) professional competences (cont.)

IVASS Valencia (SP), Eskilstuna (Sw), Irecoop (It)

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Clients needs; professionals tools and competences disaggregated by inclusive and self-determination approaches; and operational/organizational levels - overview

	Inclusive principle	Self-determination approach	Inclusive principle	Self-determination approach
	Clients needs		Requirements (Competences and tools)	
Organizational level	<ul style="list-style-type: none"> - Better reliability of the provided service - Better responsiveness to clients needs - Higher resources, better quality protocols and systematic evaluation procedures - improvement of stakeholders relationship (networking) - Openness to ongoing change - Professionals' lifelong learning approach 		<ul style="list-style-type: none"> - Evidence-based practice: Giving tools to professionals to improve their theoretical knowledge, knowing how to distinguish reliable sources; knowing how to measure the results - Stakeholders theory and networking approach 	
Professional level	<ul style="list-style-type: none"> - The right to access to supports where clients wish to get older. - The right to live within their communities 	<ul style="list-style-type: none"> - The right to make their own choice regarding their future - The opportunity to acquire skills to empower them to have control of their lives 	<ul style="list-style-type: none"> - Communications skills - Ability to adapt to different situations and needs - Skills to putting knowledge into practice - Learn how not to be overprotective 	<ul style="list-style-type: none"> - Knowing how to understand the context and work with family to design and implement personal projects - How to teach cognitive skills. - How to work cooperatively with stakeholders

Within this holistic paradigm, training is recognized as an effective mechanism for improving employee performance and delivering better organizational outcomes.

Finally, both levels of action should assure the promotion of an evidence-based practice, obtained from reliable sources, which support the applied theory.



Ageism and Quality of Life

Miljana Déjanovic - Dep. Val de Marne (F); Jill Mattsson & Monica Tola - Karlstad; Jorrit Campens - Ghent University College



How can the representation of ageing influence the quality of life of ageing people with disabilities and the quality of their support ?

The project TRIADE was initiated within a specific demographic context in the world and more specifically in Europe, based on ageing of the population. According to the World Health Organization, the number of people aged 60 years or older will rise from 900 million up to 2 billion between 2015 and 2050 (moving from 12% to 22% of the total global population). This is also true for people with disabilities and more specifically for people with intellectual disabilities, who are living longer due to better health care and qualitative support. It is relatively new to see that people with disabilities live longer than their parents do: this raises a new societal challenge with an urge for adaptation and efficiency of

formal care.

According to the partnership, this challenge creates a need to develop models of close collaboration between sectors of elderly and disability - giving more specific and adapted care and support within the context of community based support.

Also, there is a strong need to improve the way ageing and people with disabilities, particularly people with intellectual disabilities, are perceived – the image of ageing in general has deteriorated during the latest decades. This is a most important barrier to develop a supported public policy and to get the work with elderly more efficient and more attractive. During the exchanges of practices, it has been observed that the negative image of elderly (with a disability) influenced both quality of life of the elderly and the quality of support delivered by the professionals.

What is the phenomenon of ageism ?

According to R. Butler, ageism is considered as ‘the systematic stereotyping and discrimination against people, simply because of their age. The image of old age and older people is derived from an array of prevailing political, economic and social attitudes as well as from historical developments.’ Puijalon & Trincaz state that age discrimination is as present as racial or gender discrimination is.

Furthermore, it is very interesting to read how Marcia Ory from university of Texas describes the perception one has on ageing people giving an overview of six common myths.

To be old is to be sick (Reality: Although chronic illnesses and disabilities do increase with age, the majority of older people are able to perform functions necessary for daily living and to manage independently until very advanced ages.)

You can't teach an old dog new tricks (Reality: Older people are capable of learning new things, and continue to do so over the life course. This relates to cognitive vitality as well as the adoption of new behaviours.)

The horse is out of the barn (Reality: The benefits of adopting recommended lifestyle behaviours continue into the later years. It is never too late to gain benefits from highly recommended behaviours, such as increasing physical activity.)

The secret to successful ageing is to choose your parents wisely (Reality: Genetic factors play a relatively small role in determining longevity and quality of life. Social and behavioural factors play a larger role in one's overall health status and functioning.)

The lights may be on, but the voltage is low (Reality: While interest and engagement in sexual activities do decline with age, the majority of older people with partners and without major health problems are sexually active, although the nature and frequency of their activities may change over time.)

Older people deserve to rest (Reality: The majority of older adults who do not work for pay are engaged in productive roles within their families or the community at large.)

What is the importance of Ageism in working with ageing people with a disability?

It's clear that professional's attitudes towards elderly influence the Quality of Life of elderly in general and of people with disabilities getting older. Many authors conclude that ageism undermines the quality of health and social care. As Sevilyay Senol Celik demonstrates ‘today's students are tomorrow's health care professionals, the development and cultivation of positive attitudes towards ageing and older people is crucial.’

Also, Quality of life of elderly and ageing with a disability depends on their self-perception of ageing, based on the same stereotypes associated with the physiologic state, functioning and longevity.

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Ageism and Quality of Life

Miljana Déjanovic - Dep. Val de Marne (F); Jill Mattsson & Monica Tola - Karlstad; Jorrit Campens - Ghent University College

(cont. from p.7.)

How to overcome the ageism and stereotypes?

Ageism is a serious issue that should be treated the same as other types of discrimination.

In May 2016, the World Health Assembly adopted a 'Multisectoral action for a life course approach to healthy ageing: global strategy and plan of action on ageing and health' covering a 14-year period of sustainable actions towards elderly and a global campaign against ageism.

For example **on political level**, public policies need to intensify their actions towards promoting healthy ageing, by recognizing ageing efforts and by creating a strong coordination by the different actors of elderly and disability care. From the practical point of view, **education could play a very important role** in combatting ageism.

According to Prudent & Tan 'educational programs at all levels, starting with elementary school, should promote intergenerational contacts. For example, at the elementary and high school levels, content on all life stages, including older adulthood, should be integrated into curricula. In addition, intergenerational contact could be expanded through linking elementary and high school students to older adults. Activities such as visits to residences with older adults and volunteering to share skills, resources and record life histories would provide opportunities for interaction that could shape positive attitudes toward the older adult. Staying at work, volunteering or joining a community group helps people to stay physically and mentally active for longer.

EU News

Elena Curtopassi - ENSA network



The next European Week of Regions and Cities will take place from 9 to 12 October 2017 in Brussels. Pin the dates in your calendar and visit the [2017 event's website](#) for updates.

discover now the 130 workshops, networking events and project visits organised in Brussels as part the 15th European Week of Regions and Cities!

Under the headline 'Regions and cities working for a better future', the programme tackles three main themes: Building resilient regions and cities – #LocalResilience; Regions and cities as change agents – #TakeAction; Sharing knowledge to deliver results – #SharingKnowledge. 28 partnerships of regions and cities, 14 Directorates-General of the European Commission, several networks, associations and other institutions have partnered up for it. The Opening session takes place on 9th October in the European Parliament.

Selected event

The Covenant of Mayors Community: coordinated local action as a blueprint for national policy frameworks 10/11/2017; 14:30 - 17:00- Code 10B36

Special Invitation

Cohesion policy at stake; why we still need it?

Venue: Fundacion Galicia 11/10/2017- Time : 14.30 18.30

Within the theme Regions and Cities as change agents, the Consortium Europe of Traditions coordinated by the Veneto Region with partners from Galicia, Lazio, Nordland, Union of Municipalities South Aegean Region, Union of Municipalities of Attica Region, Kujawsko-Pomorskie, Opolskie Region, Silesia, Norte de Portugal, have the pleasure to invite TRIADE partners to the workshop addressing governance and the social dimension of cohesion policy post 2020 -Code 11B101.



Quality of Life of ageing people with disabilities and the contribution of informal caregivers

Irene Wiezer - City of Rotterdam



General policy in European countries is to encourage people to live independently in their own houses for as long as they can. The underlying reasons for this are simple but pressing in most countries: an aging population, rising care costs and the anticipated labour shortages are necessitating cost control measures and other interventions in the care system. With the growing number of ageing people with disabilities in European Union, the task to ensure health and social care is growing. Many people may require assistance in the short or the long term. Formal care remains a very important part of providing care, but informal care becomes more and more usual way of assistance and the contribution of informal caregivers and volunteers to the care system is increasing. The extent to which countries develop active policies and approaches on how to reach informal caregivers whom care for an ageing person who lives at home and how to develop services to support and relief them varies depending on the cultural and political background of the country. In the presented practices of the TRIADE-project in Valencia, Val-de-Marne and Rotterdam, the topics that were discussed included the cooperation between the professionals and the family caregivers, and also different ways to support the family caregivers of ageing people living at home. All partners agreed on the relevance of interpersonal relations and the important role informal caregivers play in their client's life.

Besides the daily assistance that a person with (mental) disabilities may need, the quality of life of ageing people with mental disabilities is to a considerable degree determined by having meaningful relationships. Family caregivers (or caregivers within the social network) are part of the social network of the client. They often have a long-lasting and intensive emotional bond. For clients still living at home, as well as for clients living in an institution or sheltered home, informal caregivers are, and always will be, an important and constant factor in their lives. Therefore, the informal caregivers, if taken into account by professional caregivers, can contribute significantly to the quality of life of the client.

Informal caregivers whom care for an ageing person who lives at home don't recognize themselves as caregivers, and do not ask for any kind of support. In some occasions, the informal caregiver may become very protective over the person with an intellectual disability and require knowledge on how to empower the person with the intellectual disability to participate in society. Support for informal caregivers is also needed, as they can become overloaded with work, risking experiencing feelings of isolation, psychological depression, and even physical health problems.

How can informal caregivers be supported? To begin with, public authorities should recognize the caregiver statute and define caregiver rights. Furthermore, public authorities and actors in the field of health and medico-social care should develop strategies and actions of communication to help people recognize themselves as informal caregivers of elderly individuals or individuals with a disability. By recognizing this informal caregivers can demand support in fulfilling their task effectively. Actors in the field of health and medico-social care should additionally develop services that effectively support and relief them.

When the client receives professional care at home, in an institution or a sheltered home, informal caregivers still play an important role. Although the daily care may be taken over by professionals; because of the (long-life) relationship, family and friends still can contribute to the quality of life of the ageing person in different ways. The family caregiver can be seen as a partner of the professional in providing the best care for the client and can be an informant (however sometimes a personally and emotionally involved informant). The informal caregiver can also be a client themselves, when they are in need of support. Taking this into account, the professional needs to cooperate with the informal caregivers and support and facilitate them, in order to maximise the quality of life of the client. Actors in the field of health and medico-social care and educational institutions should collaborate in the investigation of finding which instruments and interventions strengthen the relationship between professional and informal caregivers. They should also focus on the effects of policy and measures to support the informal caregivers. Professional organizations should provide training and education for professionals to recognize the signs of physical and psychological fragility of caregivers and strengthen prevention of bad health.

The Triade partners also discussed the contribution of volunteers to the social participation of ageing people with mental disabilities and, through that, contribute to the quality of life. *cont. p.10*

Quality of Life and the contribution of informal caregivers (cont.)

Irene Wiezer - City of Rotterdam

(cont. from p.9)

The level of contribution in the health sector of volunteers, which consist students, retired people, or the unemployed, and the way it is organized varies considerably, depending on the cultural and political background of a country. In most countries the concept is relatively new. Volunteers supporting elderly people, vulnerable locals and others with a small social network (who may or may not live in an institution) contribute to the quality of life of these people and therefore also contribute to an inclusive society. In a changing society with smaller families and larger mobility (i.e. family is not living nearby), the contribution of volunteers provides opportunities. What is needed to stimulate and facilitate volunteering should be further investigated. Public authorities should develop adaptive strategies to different kinds of community care and welfare. Strategies that create awareness and initiate public debate regarding the importance of volunteers in the contribution of the quality of life of the disabled, which contributes to a more inclusive society, should also be further developed. Framing this as saving costs is a bad motive. Social institutions and corporations should develop methods and organisational models to support and facilitate voluntary commitment and to recruit new (younger) groups of volunteers. Organizations of (institutional) care should invest in the education and accompaniment of volunteers and should facilitate the collaboration between professional caregivers and volunteers (by defining the responsibilities and increasing trust).



EU News

Elena Curtopassi - ENSA network

26 April 2017, **the reflection paper on the social dimension of Europe** raises questions on how to sustain our standards of living, create more and better jobs, equip people with the right skills and create more unity within our society, in light of tomorrow's society and world of work. https://ec.europa.eu/commission/sites/beta-political/files/reflection-paper-social-dimension-europe_en.pdf

COHESION POLICY POST 2020- Call for action

EU Cohesion policy supports the social inclusion of people with disabilities. For 2014-2020 three priorities addressed had an impact for the TRIADE consortium interests in the field of the quality of life of ageing people with disabilities: promoting social inclusion, combating poverty and any discrimination; investing in education training and life long learning; promoting sustainable and quality employment and supporting labour mobility.

What will happen to these thematic objectives if the allocation of the share budget would change?, how could we ensure these priorities for ESF?

TRIADE - ideas and reflections - a preview to our suggestions for future actions towards an inclusive approach



Sharing successful (and not always easy to realize) practices and inclusive policies is a most fascinating activity, especially when it takes place in a relaxing atmosphere, with open minded partners (friends...), who want to contribute – by doing so - to an *inclusive* society, one that is accessible for all citizens. Moreover, as this activity also creates a higher level of intrinsic motivation and enthusiasm to realize the transition to community based systems of support, a need to share the *lessons learned* and suggestions for future actions arises.

The TRIADE partnership has summarized the lessons learned: a *final report* with suggestions for future actions has been produced and will be disseminated widely.

Without revealing the complete content of this report, this small contribution in the final TRIADE newsletter #5, will focus on the main ideas of what the partnership wants to present as starting points for future actions.

Undoubtedly, the Quality of Life concept is the core topic. This concept needs to become the principle that gives direction to policies and management (macro and meso level) and to the content of educational curricula, in order to 'produce' professionals that approach ageing persons (with or without disability) from a social, inclusive model. The concept should become the starting point for every system of support – independent the environment and cultural context – as it is the heart of the 'universal' rights and not only determined by objective, but also – and especially - by subjective, personal factors. It should be defined as an outcome to be monitored and evaluated continuously, as a basis for quality management of a service.

In this model, although the focus is on the client, the framework is the client's focus!

The partners feel the need for a good assessment tool to see to what extent interventions contribute to quality of life, and promote the idea to align all regulations, subventions, audits,... to the concept. Existing tools to assess support needs need an extension of the individual perception of his/her quality of life, without ignoring continuous processes of dialogue, negotiation and reflections.

'New' curricula for 'new' professionals, giving evidence of working according a holistic approach, need to be considered, taking into account not only skills, but also attitudes and belief systems. For the actual staff a systematic and coordinated training curriculum should be part of the VET-policy.

A community based support will not be realized, when 'fields' (for the elderly or the 'disabled') work independently – an intersectoral approach beyond the fields is a critical condition to realize the transition we have in mind. Not only the professional is at stake, the social network of the client and informal caregivers and volunteers – being illustrative for an inclusive society - need and have the right to get a systematic support. And when all kind of (negative) perceptions on ageing and disability can be replaced by a systematic attempt to give ageing people an active role in the society, quality of life and quality of support will profit.

These ideas are only part of the reflections to be found in the report. This report can be downloaded from the [TRIADE website](#) after November, 1. Enjoy reading the report!

Social Agenda 48 is out with a special feature on the European Pillar for a social Triple A. The social Pillar is already operational. The Pillar of Social Rights is about **delivering new and more effective rights for citizens**. It builds upon key principles, which include Equal opportunities, Social protection and **inclusion**. If it aims to provide an incentive to act and to ensure that EU legislation effectively improves people's life. **The European learning network of TRIADE Partners offer its reflections and recommendations for the support of ageing people with disabilities.**

http://ec.europa.eu/employment_social/social_agenda/books/48/en/

GENERAL EVALUATION of the TRIADE PROJECT

Miljana Dejanovic - Val de Marne



This global overview presents the results of a survey amongst the partners of the consortium and contains four evaluated items covering the complete project period : structure, content and delivery of transnational meeting, quality of transnational partnership, project management, and quality of dissemination. Evaluations were held after each meeting, halfway the project and after the final meeting in Sweden. Almost all individual partners have participated in six evaluations except the partner from Sint Vincentius who didn't participate to the Rotterdam meeting. It is important to underline the subjective nature of the evaluation : opinions are different from one partner to the other.

Regarding the structure and delivery of transnational meetings, some of partners are completely satisfied on the hospitality of the hosts of the transnational meetings, the quality of the information received before the meetings, and the quality of the communication with the hosting organizers. Almost all scores on these items were maximum scores (4), only a few are 3-scores. There are no 2 or 1-scores.

Partners have different opinions on the quality of the partnership. Even if the partnership has made a significant efforts to improve the quality of his exchanges and mutual understanding by the end of the project, the beliefs are that not every partner did contribute to the same degree to the meetings or didn't work hard (22 answers corresponding to the measure 4, 29 answers to the measure 3 and 4 answers are equivalent to the measure 2 on the scale form 1 to 4. For a good understanding, several partners testified clear proof of the efforts done : *« I think that everyone had so much to say and contributed to the discussions on a wonderful way. Everybody was so tired but we couldn't stop talking. It was a very intense and creative meeting. », « I liked the interactions we had afterwards, when discussing the different topics on 'informal care' and 'the new professional'. They gave us all an idea of how each country still has a different perspective on care due to their specific history or culture. Still it was possible to understand each other and we were able to come to some shared goals that could lead to an overall innovation and improvement the life of elderly people with a disability. »*

Regarding the part related to the project management, this process improved during the partnership. The project coordinator fulfilled with success its mission and could lead partnership to the desired outcome, to formulate suggestions and recommendations for better inclusion of ageing people with disabilities. The improvement of project management has been observed since the mid-term evaluation, once information and practices could be summarized.

Concerning the dissemination part, the partnership has divergence regarding the clarity of the dissemination plan and tools. But it is important to mention that the most important dissemination of the project results has been made through the whole network ENSA and especially through the ENSA elderly and disability working groups meetings organize two or three times per year. The newsletter was a good tool to give evidence to the progression made. A final meeting to share the results will take place at the very end of the project lifetime.



In conclusion, according to the evaluations of the whole project, the interim evaluation and the final evaluation, the project ends as partners had in mind at the beginning. The partners seem to have the same expectations about the results and have worked hard to contribute to the project. Also, the evaluation reports show that they have learned about the different ways to support ageing people with disabilities - being aware that there is not only one way to do. The most important thing is to continue to create an inclusive society where the quality of life of ageing people with disabilities is the main goal. Some of comments support this conclusion :

« It was our pleasure to participate as a partner to such a project. We learned a lot about different European approaches on how to make an inclusive society for ageing people with disabilities. »

« I was very pleased and inspired by the cooperation of all partners during the discussion sessions. I learned a lot in those few hours which I can take back to the university college students. »



Report: Successful Swedish TRIADE meeting in Karlstad & Eskilstuna, June 2017

Sara Morgan, Monica Tolla, Marie Skoghill & Jill Mattsson



For the last regular conference, we were happy and excited to invite everyone to Sweden. We wanted to share our work and some good practices that enhance the participation and the inclusion of service users. Also, the Swedish system, regulations and economy has been explained to understand the foundations of the support system.

We started in Eskilstuna municipality, a municipality of 100.000 residents. Good practices (PFA, Pedagogical attitude and wayso of working with people with intellectual disability) were presented. PFA - starting from from each person's individual competences - quality of life and autonomy are fostered. To work with PFA equates a craftsmanship where the goal is individually adjusted support to individuals with ID. PFA focuses on staffs' changed and adjusted attitude and way of work adapted to the individual's specific abilities and needs

We were also shown how Eskilstuna organizes education for and with service users to prevent violence - a method called V.I.P, especially produced for our service users with intellectual and mental disabilities. V.I.P stands for very important person; the aim of the V.I.P.-program is to minimize the risk for the person with disabilities of exposing her or himself of destructive relationships. To minimize the risk of getting abused by others, or abusing others we work to increase the disabled person's self-esteem. Through reaching more and a better awareness of their own feelings, training their personal boundaries, we can increase the participant's possibilities to make better choices in different situations. Some reflections from the participant have been "I always have the right to decide over my life and my body. I decide what feels wrong" and "to speak up".



After the Eskilstuna sessions we traveled to Karlstad Municipality, a municipality with approximately 90.000 residents. The Pict-O-Stat client survey has been presented.



The purpose of this tool is first and foremost to increase the participation in customer and client surveys for people with intellectual disabilities, by making it easier to answer questions about the support they get from the municipality. Service users express their good feeling about this system as they undertand better the questions and the responding system. IPadsmake communication and planning easier .

Karlstad also presented a group residence for older people with intellectual disabilities as a way to face the problems that occur when needs are changing. The staff of this residence has been "geared up" to better meet the new needs : lectures and conferences, collegial observation, exchange of experience and

consultation by a dementia nurse were tools to broaden competences. The staff participates in a web training project for staff and for users and their network.

To discover changing needs as early as possible, a mapping tool and a checklist has been developed. This tool can be helpful in doctor consultations but for whatever support.

A final good example was presented at a resource center for support, smart solutions and technology. We were able to visit a model apartment, which has smart tools to manage everyday life.

During the three days in Sweden we also worked on the themes and the conclusions for the final report., to be presented later this year.



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**ENSA ELDERY AND DISABILITY
WORKING GROUP
will meet in BRUSSELS
(Veneto Region Brussels Office)
on Monday *December, 52* 2017**

**TRIADE PARTNERSHIP will meet local
stakeholders to reflect on the final report
on Tuesday *December, 53* 2017
in KORTRIJK
(vzw den achtkanter & Sint Vincentius**

on the (draft) agenda
Study visits
Reflection on the TRIADE report
Future project

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Thanks to everyone who has contributed to this newsletter
Responsible editor : Johan Warnez