

THEME 4 – The New Professionals

1. INTRODUCTION – definition, relevance

1.1. A changing society with increased numbers

For the first time in history, a significant number of adults with an intellectual disability are living into old age. The average life expectancy for a person with an intellectual disability has increased from about 20 years in 1930 (Carter & Jancar, 1983) to approximate that of non-disabled citizens living in the late twentieth century (Janicki, Dalton, Henderson & Davidson, 1999; Patja, Iivanainen, Vesla, Oksanen & Ruoppila, 2000). While the attainment of late life represents a significant achievement for people with intellectual disability, increased life expectancy has resulted in growing concerns about the extent to which disability service providers are ready to meet the changing needs of increasing numbers of older people (Australian Institute of Health and Welfare [AIHW], 1997, 2000; Fyffe, Bigby, & McCubbery, 2006; Wilkinson, McCallion, Fleming & Kerr, 2004).

Concerns also exist regarding services' ability to support older people with an intellectual disability to 'age in place' (Williamson & Harvey, 2007). In numbers older people with intellectual disabilities is a significant group of citizens whose needs often are overlooked, their voices are not heard and their health, well-being, quality of life and possibilities to be active citizens are largely circumscribed. Despite this they are largely invisible in European strategies like Europe 2020 and Horizon 2020. From an EU point of view, this is neither morally or socially nor economically acceptable. EU is to ensure all its citizens human rights, the right to social and political participation and dignity. This is also a group who often are cared for by informal caregivers or professional caregivers who are women with a low level of education, low status and low wages – facts that mirror structural gender inequality and impacts on these people's health and quality of life.

As a consequence, the health and care of the rapidly growing older EU-population and elsewhere poses a number of specific challenges. One is the burden posed by mental and neurological conditions on older citizens which impacts on their working capacity, well-being, quality of life and that of their care givers, and interacts with the course and treatment of comorbidities associated with old age. One challenge in re-designing health and social welfare systems is to develop integrated care models that are more closely attuned to the needs of patients and older persons, their relatives, caregivers and health and social welfare organizations. Such care models should be multidisciplinary, well-coordinated, anchored in community and home care settings, and proactive and patient-centered rather than reactive and care and social provider-centered.

Furthermore, public health, biomedical, social and behavioral research has provided evidence for new approaches to prevention, primary care and treatment. The integration of such approaches into health and social welfare services requires cooperation across sectors and between stakeholders, and challenges the current boundaries and established norms of operation. To achieve such cooperation has been proven difficult.

Older people with intellectual disabilities have the same rights, needs and competences as other older people and specific care and social service needs. Still, in the development of more end-user-oriented care and social services older people with intellectual disabilities are overlooked or excluded. Often these people and their informal care givers are not involved in decision-making, nor are their capacity and willingness to express care preferences and needs considered or their ability to administer self-care and adhere to care plans appreciated.

Actually the ageing in place principle is a leading inclusive principle. According to this principle, the elderly – if this is his or her choice – must be supported in the place where he wishes to become old; when this is not possible anymore (due to e.g. needs that transcend the competencies and means of the service provider), transfer of the disabled people to the regular service for the elderly, including a qualitative support, must be possible.

1.2. An inclusive way

Article 2 of the United Nations Convention on the Rights of Persons with Disabilities states that, “Persons with disabilities include those 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”. Services and social workers should therefore be an existential guarantee for people with disabilities and not just in care environment, cognitive skills, or motor or professional skills. This means that the center of the inclusion process there are no pieces of individual but the individual itself, thought to be the original bearer of an existence capable of fulfilling itself.

At the operational level, this perspective thinking leads to the fact that socio-educational accompaniment to the realization of a life project fulfils the wishes of autonomy, according to an operating mode that takes into account the ability of everyone and everyone to choose. It is clear that this challenge opens up the capabilities of all subjects, including that of social workers, allowing seeing completely renewed and different work horizons for social workers and the functions they should perform.

1.2.1 Emancipatory function - direct action towards people with disabilities and their families

* Support self-determination processes, which are the possibility for people with disabilities 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 him to explore the dynamic desire-reality and to increase his awareness and positioning capacities within reality.

* The recognition and support of the different phases of the life cycle of a person with disabilities, with particular attention to the adult and elderly dimension;

1.2.2 Return function - relationship between people with disabilities and territory

* The promotion of recognition of the social role of people with disabilities, that is the ability to express an active position and participate in the context they live in, taking responsibility (small or large, durable or temporary) in relation to needs and opportunities in the daily flow of social cohabitation;

* Promotion and support for proximity development, that is the development of relationships and ties that go beyond the parent-operator couple, and which amplify diversify and make mobile, plastic, varied, the circuit of vital relationships and introduce implications dynamics and mutual change between different identities that can evolve and improve, mutually affecting;

1.2.3 Transformative function - participation from services to the affairs of the territory

* To make the social value of disability express and thus contribute to the quality of life of all. For a service, a project to be done to improve its social context means developing a mutualistic relationship that legitimizes, through concrete practices, the right of citizenship within normality, and contributes to building and extending its boundaries. Operators should be able to support people with disabilities to take an active part in building up the living conditions and to contribute to expanding the social capital of communities and territories.

In this macro-framework the social worker should assume the role of process mediator and hence be able to:

Promote a networking approach to the promotion of social inclusion processes and building bridges between services and companies, to be able to build significant relationships with local stakeholders in order to offer inclusive opportunities to people with disabilities. They should also promote a culture of inclusion with all the resources of the territory and taking the role of the facilitator/accelerator of networking processes. They must know how to play a mediating role between the contexts of life and the characteristics of the person with disabilities (context adaptation processes, relational facilitation and so on).

The social worker must also recognize that the relationship with person service user is temporary, in the logic that people should be able to live and act in the community. People with disabilities must increase their ability to “stay” in society. This means supporting the development of the ability to "learn to impregnate" people with disabilities and seize any opportunity to train / develop cognitive skills and to experience "risks" to people with disabilities in the perspective of increasing the potential autonomy and to experiment with authentic social roles.

The professionals need to recognize the person as he or she was before the disabilities accompanied him or her and to take the attitude of accompanying to the person, not the person's substitute and to do that they need to focus on the persons goals with respect to the family's goals

or organizational/context needs. This requires involving the family and motivating families to change perspective from protective to inclusive. There is a need to accompany the person in emancipation from the family towards building his or hers own life project and dreams.

1.3. New challenges for professional staff

According to The Swedish national board of Health and Welfares guidance, besides the medical perspective, staff needs to have knowledge about communication, adaptation to all different situations and cognitive challenges, adaptation to the individual needs and conditions and also the knowledge of putting it into practice. We need to work to preserve functions when it comes to both physical and psychological wellbeing. Knowledge of a function preserving- and a rehabilitation way of working. Professional staff needs to have knowledge of social care in an adaptation environment with physical, psychological and social stimulation, social well-being, intellectual stimulation and an aim for a higher Quality of life.

Based on the new challenges of society and on the staff of service providers it is our belief that staff is missing the right skills and attitude to guarantee the Quality of Life of disabled ageing people. There is a need to re-skill and up-skill (new competencies, other mind set). In addition, special challenges are related to the motivation of the staff to work for/work with another target group than the group they initially have chosen to work with and to do new, more complex tasks related to physical, emotional, social and mental needs of the target group.

Training is routinely accepted as an effective mechanism for improving employee performance and delivering organizational outcomes. Further, some studies support the axiom that training results in positive outcomes for service users of disability services. Fyffe et al. (2006) reported that attitudes and skills of staff played a central role in enabling services to continue supporting people to age in place (McGhee & Dorsett, 2011).

Cooperation is also needed among different groups of professionals, to see a bigger picture, a more holistic, individualized approach of each client. Collaboration with schools is also needed, for example collaboration with VET training, in order to formulate recommendations on content and method. And to plan for how to give the best training for the work that is needed to be done, yet also how to train to keep good staff. The Triade project is based on the need for developing more inclusive and citizen centered care, inter professional and community-based care. So the question is how do we train, keep and motivate staff for this?

1.4 New competences

To facilitate an adequate attention to aging people with intellectual disabilities, it is proposed that professional caregivers acquire, throughout training processes, the following competences:

1.4.1 Regarding the intervention process

To broaden in an appropriate manner, the current evaluation protocol including tools that permit to collect data from people with intellectual disabilities and how ageing is impacting on them, on their needs, and on their quality life. Informal and formal caregivers who are close to these persons will be extremely relevant in this process, as well as the analysis if the environments are turned out on hostile areas or, on the contrary, they keep being facilitators (in case they were).

To make an exhaustive analysis about the collected information, recognizing the day by day problems in ageing people with intellectual disabilities and understanding why these problems are being generated. To determine which ones are related to intellectual disability, to the ageing process, to their environments, to other individuals' characteristics, or to the concurrence of several factors that requires a holistic approach.

To design more agile and adaptable evaluation protocols that allow a continuous adaptation to the intervention in new arising needs of people with intellectual disabilities as a result of the evolution of their aging process.

To develop individual support plans that clearly reflect the specific objectives pursued including the health promotion, the wellbeing and the quality of life as ultimate aims of the attention.

To develop adapted and effective strategies that foster the genuine participation of the ageing people with intellectual disability in the decisions that directly or indirectly involve their individual support plan. If it is necessary, take into account in this process the nearest and most relevant persons for them in quality of process advisers.

To implement programs which foster an active ageing process, with the purpose of delaying as far as possible the decline, of the people with intellectual disability. These programs must always be significant and motivators for these people as well as these must be adapted to their interests. In addition, they should never affect their dignity or be a source of alienation.

To design tailored supporting plans for people with intellectual disabilities and their families that facilitate their adaptation to the ageing process taking into account that this situation is going to need more and more assistance.

To promote the adaptation of the physic environments, materials, activities and so on, facilitating the functioning of ageing people with intellectual disabilities.

To be able to tackle the challenges related to the understanding of the new defiant behaviors that will appear in this stage. To generate the skills that permit, through a functional behavioral analysis, to answer them.

1.4.2 Regarding the relationship

To establish an excellent therapeutic rapport with ageing people with intellectual disability based on fundamental values such as empathy, the respect and recognition to the right to a dignified treatment, as well as a decent life quality adapted to their needs.

To develop communication skills to address ageing people with intellectual disability using empowering communication techniques. And to design communicative spaces where people with intellectual disabilities, can communicate their needs, preferences and decisions.

1.4.3 Regarding the organizations, coordination and work team

To develop communication channels and an effective organization and collaboration with other professional profiles to reach the excellence in the care of ageing people with intellectual disability.

To promote initiatives which consolidate a solid supporting network (informal caregivers, other resources, etc.). These initiatives will foster not only the care, but also the personal project of people with intellectual disabilities.

To plan, organize and coordinate the attention and services given by formal and informal caregivers through different entities to facilitate the best supports and personal plan to ageing people with intellectual disabilities.

To contribute to a better organization of the existing community services, allowing ageing people with intellectual disability and their families to enjoy a fully participation. To embrace an active attitude in their development, adaptation and implementation of long-term political actions related to the attention of this target group.

1.4.4 Regarding the attitudes

To demonstrate a high degree of commitment with the good practices aimed at promoting the life quality of ageing people with intellectual disabilities and their families.

To show constant improvement willingness, self-criticism, and analysis of developed processes in order to improve the quality of care given at any time.

To demonstrate commitment with the personal project, wellbeing, health and quality of life of ageing people with intellectual disability.

To avoid adopting an “ageism” attitude in the attention to ageing people with intellectual disabilities.

To always consider the planning focused on the person as central core of the personal plans to ageing people with intellectual disabilities.

To always take care of your own training, your own professional motivation and wellbeing.