WHEN “KIDS” GROW UP

For almost thirty years we deal with people with intellectual disabilities and serious dependence needs. Many of them today have become adults and for this reason we need to deliver services adequated to their needs and rights. This is the pioneer generation of aging people with intellectual disabilities who become older and forces us to reflect on issues never faced before. Since the quality of aging and services relies in the first place on personal, cultural, economic and environmental resources available to the aging person with ID, it is clear that the aging of a non-disabled person will develop very differently from the one with congenital disability. Nevertheless, it is necessary to mention that sometimes there is an overlap between the aging of a disabled and non-disabled person, due to a pathological aging and the consequences that it comes with.

There is no “threshold of old age” an age that defines exactly when a person becomes older-unanimously accepted. The World Health Organization recommends that the sixth decade of life of the person with ID to be considered as a chronological age. But the progressive loss of skills and cognitive impairment can occur even earlier either for specific pathological conditions either when the social welfare support is not adequate. If 65 years old is considered as a threshold of conventional aging, when talking about aging of people with ID the threshold considered is between 40 (for Down syndrome) and 50 years old. Some studies have shown that the severity of mental retardation can affect life expectancy: 74 years for mild mental retardation, 67.6 years for moderate, 58.6 years very serious mental impairment.

There is also an “administrative” threshold of old age that needs to be considered. It is the age when the person can enjoy the incentives for cultural goods and transport, or for access to a network of health and social services. In Italy, a non-disabled aging person is entitled to benefits after its 60th year and after 65th, the person is entitled to benefit all the dedicated service to the aging population. A person with ID instead is entitled to benefits for all his/her life since he/she is a disabled person. Moreover the person with ID rarely retires since is rarely employed and enjoys an access to the service network for disabled up to 55 years. Once 55 years old, the disabled can enjoy the grid of serves for elderly people.

In this way the aging disabled person gets out of the service network for disabled who focus more on pedagogic-enabler aspects and uses the services dedicated to elderly people more concentrated on health and care. The strengths and weaknesses of these two approaches are briefly presented in the following table :

Psycho-pedagogical approach for disabled	**Geriatric approach for elderly people**
Strength	
Person centered approach and life path projects	Use of scientific methodology
Use of the relationship as a tool	Multidimensional evaluation and global approach
Weaknesses	
Scientific weakness of the Psycho-pedagogical approach	No personalized approach - excessive standardization of the intervention and care
Reduced use of the evaluation tools and lack of attention to a multidimensional approach	Risk of medicalization of the care
No global approach	Reduced attention to the relationships and social environment

(source : Renzo Bagarolo, I luoghi della cura, 3;2005: 6-8)

If we say that the residential services for older people are often unprepared and inadequate to accommodate elderly people with disabilities (generally younger than the rest of the residents) and that the geriatric approach may not always be sufficient to deal with the problems of the disabled with ID, it is also true that many services providers for people with ID respond inadequately to the aging of people with ID since they are not providing services that match their needs and rights.

Aging is not a disease, but a process that includes losses and gains. An efficient evaluation of the pathological conditions and its distinction from the normal physiological effects of aging needs to be conducted in order to prepare the user to face better this transition. The aging of the disabled with ID, however, is almost never considered as a process that can be slowed down, modified or actively experienced, but most often as the result of a worsening of the syndrome that has produced the disability.

The American Association on Intellectual and Developmental Disabilities (AAIDD) and numerous international experts (including Christine Bigby, Nancy S. Jokinen, Anne O'Rourke and co-workers) point out that in addition to the typical needs of the aging population (appropriate opportunities for retirement, support for the grieving and the loss of family members and caregivers, maintaining social networks, quality care for health maintenance, residential adequate arrangements) aging people with ID have more specific needs due to the higher prevalence of sensory and motor impairment, the higher risk of developing dementia, the increased prevalence of psychiatric syndromes and symptoms (depression, anxiety and delirium) and the lower socioeconomic background which involves an increased health problem risk.

The professionals working with people with ID must be able to detect at an early stage all the related changes of the new and often more complex needs of the person with ID, in order to offer to the user the best possible quality of life in line with his/her interests, lifestyles and residual capacities. Supporting people with ID must be accompanied by activities that protect their right to social inclusion since much more than others people with ID are at risk of isolation and exclusion.

A new different approach in training professional and front-line staff working with people with ID is necessary such as : provision and acquisition of new skills, building a common language and a continuous dissemination of know-how between the different professionals. The training programs should include the different aspects that affect the lives of older people with ID : health and nursing, psychological, relational, nutritional, and social needs. Legal protection of people with ID is challenging today since most of them not capable of self-determination and destined, in most cases, to be represented by a family member.

It is also important to provide courses and training which could help the operators to overcome the difficulties (especially emotional/relational, but also operational) related to the aging of their users, in order to facilitate a more competent and responsible takeover.

Know-how of the training and upgraded skills shall be widely disseminated since they permit structured opportunities for discussion between the operators, all with the aim to develop efficient solutions that could match the rights and needs of people with ID.

ARFIE has been a promoter of several European projects focusing on aging persons with ID with the aim to study and exchange good practices between different EU countries on the evolving needs of aging people with ID (within the e- dignities project the countries involved were : Austria, Belgium, France, Great Britain, Portugal and Italy).

The purpose of the project was to find new effective strategies that could ensure the highest “quality of life” as possible for the disabled as they get older, investigating all areas of intervention : thought exchange know-how practices and developing innovative facilities within the services provision to disabled people. Assuming that the Quality of Life is a universal concept including an integrated vision of the biological, psychological, cultural, economic and social well-being of the user, recommendation on the EU level has been identified in the following fields :

- Health-related issues
- Housing arrangements
- Employment opportunities
- Social environment

With main focus on :

- User involvement
- Development Services
- Training of support staff
- Social Cohesion

The questions that have often risen were mainly focused on if there are many differences between aging with disabilities and aging of non-disabled. What emerged very clearly is the need to involve users as active citizens and that a lot of opportunities need to be guaranteed to persons with disabilities, even in the most advanced stage of life.
Active involvement of user/person with ID means: considering his/her will; ensuring to the user the freedom of his/her choices, supporting him/her in decision-making by providing the user with adequate time and space and active listening.

Moreover, it remains essential to allow things to go in a different way rather than how the staff had planned as to really represent the user's will and needs.

An adequate approach shall address autonomy, respect, dignity and freedom of choice as core values when supporting people with ID since it represents an approach where the solutions are not imposed but are designed and built together with the user who stays the main actor and decision-maker of his/her life path.

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