

## **Conclusion and work in progress**

*Di Catia Giaconi, Maria Beatriz Rodrigues, Aldo Caldarelli, Noemi Del Bianco*

This book aimed to analyse different perspectives and sustainable proposals to initiate new forms of inclusive planning for disabled adults. Disability in adult age creates new educational and working challenges that necessitate a rethinking of the services provided for people with disability within the scope of the Quality of Life.

Quality of Life is a complex and interdisciplinary concept that leads to interesting approaches to be applied to persons with disabilities. The challenges of schooling and working are huge for these persons and involve State, family and many professionals in order to be operated. It is also important to mention the commitment of societies with social inclusion and the systems of welfare state in different countries that lead to better quality of life. We have examined sensitive points and relevant questions involved in the evolution of these processes during a lifetime, especially in the transition between school and work for disabled adults.

QOL shows interesting integrations of the research on different fields like special education, physical and mental health, intellectual disabilities, old age and quality of life in the family. Nowadays, many aspects of these fields have been reached but three main directions stick out among the main acquisitions of the scientific community: the multi-dimensional scope of the concept, the temporal perspective and the multi-systemic perspective of the quality of life. The consensus on domains and crucial indicators allows overcoming the classic debate on ‘subjectivity-objectivity’, which concerns which dimension to include or leave out in this field. Both are essential in the discussion of QOL and should be seen as integrated sides of the same problem. We cannot treat the disabled people choices in life either as a charitable issue in a subjectivist view or pure objective and prescriptive rules of assistance.

As we have seen, to understand the quality of life of a person with disabilities, we must take in account the interactions of the subject with family, home, peers and workplace (micro-system), as much as with neighbourhood, community, available services and organisations (meso-system). We cannot forget the influence, in the quality of life of disabled persons, of the factors connected to social policies and the surrounding cultural context (macro-system).

The central guidelines in services to the person and in supplying benefits consider all these contexts, intervening simultaneously on strengthening the context and the person (in self-determination, autonomy and more) to obtain a real inclusion. In this direction, services tend to plan and implement procedures and devices to improve the context and the organisation of the services for the quality of life of people that they intend to benefit, affecting the social policies.

The late Nineties saw a surge of proposals of synthesis between the objective and subjective dimensions of the quality of life. For example, Brown (1989) considers part of the objective dimension the characteristics of the physical context, real support and stability of family relations. The same applies to the development of personal skills; the level of physical and social integration and the quality of *training* and real support; the economic (income), health and food situations, as well as the philosophy of the services, and the community. For the subjective side, the author emphasises how support and personal health are perceived, along with self-assuredness, responsibility, self-esteem, involvement and belonging to the community, as well as expectations and levels of satisfaction. Brown (1989) proposes to consider quality of life as determined by the *gap* between satisfied or non-satisfied wishes and needs, and the control exerted by the person in the surrounding environment.

On the other hand, Schalock proposed the “heuristic model” that eventually became the most used in conceptualising quality of life; this includes the studies in the field of special pedagogy. It includes eight domains of QOL: Emotional well-being; Interpersonal relations; Material well-being; Personal development; Physical well-being; Self-determination; Social inclusion; Rights; and their possible combinations.

Other studies in the fields of QOL and disability focus on the improvement of the quality of life of the subjects following de-institutionalisation and integration in the community. This improvement should be linked to a higher participation of people with disabilities to daily activities, use of the services, more interaction with meaningful people (family members, friends) and the operators of the residential structures, and to the strengthening of adaptive behaviour as well as increased possibilities of choice.

These studies provide evidence of a direct relation between QOL and self-determination in persons with disabilities: higher levels of self-determination

correspond to higher levels of QOL and vice-versa. Furthermore, several authors consider self-determination a good indicator of the effectiveness of the treatments. Other studies stress that levels of self-determination in persons with intellectual disabilities are higher than parents and operators perceive. In occupational terms, many studies show that people with disabilities perceive higher satisfaction in the lives if they are part of competitive workplaces and are involved in work related decisions.

Despite the acknowledged need to evaluate subjective factors, especially satisfaction, only few studies have been carried out interviewing persons with intellectual disabilities. They shed light on some factors that may influence the levels of satisfaction: these concern the capacity of leading an autonomous and independent life, the possibility of being productive and work as well as integration in the community. We consider important the stress attributed to the degree of personal satisfaction and self-realisation of the person with disabilities, as we will see it allows to direct strategies and educational actions toward often-overlooked dimensions, like managing free time and recreational activities.

The most accepted research orientation sustains that the evaluation of the quality of life of persons with disabilities should involve multiple methodologies, which allow comparing self-evaluations and hetero-evaluations, without ignoring direct observation.

There are many tools to evaluate the quality of life in persons with disabilities, or, more precisely the procedures that were conceived to evaluate the quality of life of individuals and used also in researching subjects with disabilities. Apart from the single procedures, the perspective of application and “measurement” of the quality of life allows viewing the person with disability in the *lifespan* perspective, to appreciate which domains of quality of life are in greater need and work on improving the well-being. Furthermore, it allows re-thinking and planning interventions and services focused on the quality of life of the person in a longitudinal perspective.

We must stress that an adult person with disabilities risks precocious ageing in terms of cognitive functions, besides natural ageing, it is due to the passage from processes of school integration and from periods of intense rehabilitation to a lack of contact with the peers, scarce free time and recreation, integration on the workplace and often a rehabilitative void. These changes intervene significantly on the quality of life of people in general and more particularly in persons with disabilities as well as to the meaning that the person attributes to the quality of life.

Apart from permanence in the family, life conditions may vary for a disabled person. There are persons who frequent socio-medical daytime centres, or small residential structures, or institutions with a high number of persons with disabilities accommodated in the structure. There are also new perspectives of *Ambient Assisted Living* using home automation systems, which allow living safely at home, however, as we have seen this path is at initial stages and it is not a sustainable solution for persons with intellectual disabilities. Here too, situations do not all focus concretely on the concept of quality of life, since even in cases where an adequate assistance is available, practices of maintenance and improvement of the quality of life remain only an abstraction.

For people with disabilities the opportunities of personal enrichment and learning decrease with the time. Usually, the educational activities proposed are repetitive, scarcely significant and in line with the chronological age. Decline is in any case slowed down in persons who continue to live in stimulating environments from the educational and skill-training viewpoint, as it does not depend strictly on age, but on variables like the severity of the condition or other pathologies.

Autonomy belongs to the capacity of action of the person with disability referring to the system of personal preferences and interests. Therefore, the ability to take decisions and making choices. In the hetero-evaluation questionnaires of quality of life, the outsider associated with the disabled person is asked to bear in mind the look and facial mimics or the tone of vocalisations of the person, even if he/she is afflicted by multiple disabilities, to understand his/her mode of communication, approval or disapproval for an object or activity.

Over time, subjects with disabilities run the risk of having fewer and fewer opportunities for integration and participation in the community. The places that they usually frequent are home and always the same restricted social environments, when inserted in a residential centre that structure risks to become the only place they visit. At participation level too, in every subject, the degree of maintenance or empowerment needed for inclusion can vary considerably. The context is of extreme interest because, leaving planning apart, it leads, among other things, to ask ourselves what has to change to improve the quality of life of persons with disabilities and social inclusion, even when the level of adaptability is low.

The ageing of the persons with disability poises remarkable challenges. This complex picture has several reading keys and different levels of complexity. Some authors consider the consequences at social level, therefore the fall-outs on the

individual well-being and on the level of the economic and social costs. In the perspective of the special pedagogy come significant educational experiences, in re-thinking routes and actions to construct life plans under the aegis of the quality of life.

Apart from the economic situation of the family and the reaction of the community, the failure of caregiving is also due to the lack of a network to support the family, which should prepare on the possible specific choices for the life-plan of the family member with disabilities. A network to take care of the adult with disabilities and his/her family should be at the centre of the personal project to the decisional process toward a better living condition, to respond professionally and in a planning mode to the delicate phases of transition from adolescence to adulthood of the person with disabilities. We believe that in persons with disabilities life trajectories must be meaningful trajectories. This cannot become true if the network of services stops supporting the family and the person with disabilities in the delicate phases of transition.

The welfare state is the system that guarantees satisfactory living conditions of a population, projected and practices by a State. In other words, it is the project of social justice transformed into assistance to the population: housing, work, education, medical assistance, minimum income, benefits, social security, retirement, among other conditions of dignified life. Well-being, or Quality of Life, is a dynamic concept, a mobile line, which accompanies social changes and necessities in a given reality. Following this line of thinking, associating it with the historical data above, we can perceive that, in the last decades, the neo-liberalist political and economic framework points toward a new direction for the *welfare state*.

The concept of diversity continues to expand absorbing other groups. Talking about diversity means, apart from the already mentioned groups, talking about many other groups, like people with different physical or mental abilities, people with sexual orientations different from heterosexual, migrants, refugees, and many others. Therefore, diversity is a dynamic concept subject to constant social changes. Whatever was different in the past continues so, however, new groups enter this continuous movement.

We considered in this book different models of well-being in two countries, Brazil and Italy, and their influence in the social inclusion, we presented data from case studies derived from our professional experiences. We started from the personal knowledge of the Italian system, with an experience of many years as psychologist

and educator in attending children and teenagers in conditions of learning and developing deficit. We continued from the experience as a psychologist and professor in Brazil, working and researching with disabled people.

In both cases, but with consistent differences, at the end of the school cycle, the young with disabilities and his family run the risk of not finding an integrated system to allow widening autonomy, participation and integration within the community. For some youngsters school exit means the social context shrinking, instead of the desirable living in environments different from the family one and the choice of recreational activities and free time.

The complex scenario of the subject of this book, which recalls a wider conceptualization in relation to social inclusion and Quality of Life of adults with disabilities, focused on the work as a privileged way for people to recognise themselves and be recognised as adults and, consequently, assuming an adult identity in terms of participation and active citizenship.

Work, even in its ambiguous aspects, critical issues and potentials, limits and self-realisation, remains of essential importance in the life of a person. An effective path to employment brings an improvement in the Quality of Life of the person. Surely, work allows us to meet with our limits and requires new modes of communication, different forms in relations, responsibilities and co-responsibilities and a path to self-awareness.

Organisations can benefit from people with different abilities when they enter the productive age if they have been encouraged and helped in their development. Social inclusion and living daily situations with other people, are essential for everyone, regardless of intellectual and physical development. If this slice of the population is segregated in special schools and institutions, we condemn them to live a “special” life, “customised”, in a fashion, often, dictated by preconceptions about their potentialities and the targets that could be reached. A life cannot be based on stereotyped patterns, below dignity, in conceiving people immature and incapable to understand and choose their future.

The life trail becomes meaningful for the disabled person within a life plan suited to the characteristics of the quality of life, for instance, taking into account occupation, training opportunities also at university level, internship, working insertion and protected workplaces. We believe that, for persons with disabilities, the trajectories of life must be trajectories of meaning. This cannot be realised if the

network of services stops supporting the family and the person with disabilities in the delicate phases of transition. Sharing the choice of a life path makes sense in realising a meaningful project.

Finally, these experiences exposed here prove that people can find realisation through work and be productive within the organisation. Diversity became appreciated by managerial literature as a possible mode to gain in competitiveness and provides fresh ways to look at the outside world. Various argumentations could sustain the above, from financial investments to human values, enabling intermediation and resolution of the problems, as it facilitates the approach of the problems in a different light. The theme gains relevance, but little is published on the policies of human resources management and its operations directed to this public. We perceive the difficulties to recognise and interpret the theme, with the consequent inability to resolve concrete situations, which can overcome the tendentially discursive aspect of the debate. Diversity should be studied in relation to possible gains in productivity and performance.

However, nothing can be done without solid pedagogical bases in the education of young students to support individual and collective development, and, at the same time, prepare the individuals to life and work. Legislation, norms and clear procedures are needed too so that institutions can work in harmony and allow individuals to walk on their paths of life and work in a productive and satisfactory manner.