Inclusive Education

The theme of this book is the “Inclusive Education”, it is inherently important in the present society, where people live longer. Health care and long term welfare are essential in the prospect of a longer life expectancy, trying to avoid a substantial impact on the cost of public healthcare and for the families. The theme becomes very relevant if we take in account the life of people with disabilities, with different levels of physical and psychic dependence. The authors of this book believe in this: another society is possible, it can grow taking in account the characteristics of groups and individuals with special needs and planning ways to help on these needs.

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978-620-2-08324-9

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Perspectives, reflections and case studies

edizioni accademiche italiane

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Edizioni Accademiche Italiane

Imprint

Cover image: www.ingimage.com

Publisher:
Edizioni Accademiche Italiane
is a trademark of
International Book Market Service Ltd., member of OmniScriptum Publishing Group
17 Meldrum Street, Beau Bassin 71504, Mauritius

Printed at: see last page
ISBN: 978-620-2-08324-9

Summary

Introduction: Education for all and Quality of life

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

The theme of this book is the “Quality of life”, it is inherently important in the present society, where people live longer. Health care and long term welfare are essential in the prospect of a longer life expectancy, trying to avoid a substantial impact on the cost of public healthcare and for the families. The theme becomes very relevant if we take in account the life of people with disabilities, with different levels of physical and psychic dependence.

World Health Organization data show that approximately 15% of the world’s population lives with some form of disability. It has been estimated that globally about one billion people have disabilities. These numbers grow as they are associated with the ageing of the world’s population, along with the increasing sophistication of the tools that diagnose the disabilities (WHO, 2011). On one side, longer life expectancy can be considered a social improvement. On the other side, adapting to it brings important challenges for governments, care-giving institutions, families and the general population. The question involves everybody, notwithstanding the prejudices and misinformation that still concern it.

Actions to increase awareness and sensibilization toward older and disabled people have been proposed and implemented. We could mention many local examples, however, at global level we find the proposals by the World Health Organization: World Report on Disability (2011), Global Age-Friendly Cities (2007), Active Ageing (2005). These document’s main contribution aims to promote the discussion on the themes and the responsibilities of all the agents involved and concerned by by the new demographic reality.

Bauman, who put the faults into theoretical perspective, draws our attention to the implacable times we live in. Our competitive times despise the weakest, where few are interested in concepts like community, collectivity and cohabitation. Excessive individualism weakens human ties and strains the capacity of being empathic and supportive, in a increasingly global world (Bauman, 2003; 2007).

Paradoxically, the most diverse news, from far away countries, arrive instantaneously just with a click online, while we became incapable to deal with the nearest problems next to us. The rhythm of change tends to be far too fast, and equally the speed with which new phenomena appear and disappear in the public awareness is very fast. These are times where each individual is left abandoned, without any consideration from those living in the same community (Bauman, 2009).

However, this indifference should be fought with new ideas of inclusion for people with disabilities. The authors of this book believe in this: another society is possible, it can grow taking in account the characteristics of groups and individuals with special needs and planning ways to help on these needs. Dealing with diversity does not mean overlooking or hiding it, but to give it a meaning and contribute to overcome it.

The book is organised in four chapters. The first chapter brings different perspectives on the necessity to have sustainable proposals to initiate new forms of inclusive planning for disabled adults. Adult age disability creates new educational challenges, it asks to the services provided for people with disability within the scope of the Quality of Life.

As authors and researchers of special pedagogy, we consider our focus to be the creation of the concept of *Quality of Life* (QOL), which will be explored in this chapter and will demonstrate its conceptual and professional potentials; including the field of special education and perhaps more relevantly, the scenario of the pedagogy of inclusion.

The philosophical, medical and economic considerations of this ubject will be examined with a multi-disciplinary analysis only within the scope of conceptualisation and appreciation of the quality of life for disabled persons. Remarkable reflections and pedagogical implications arise from taking care of adult disabled persons. They range from organising daytime and residential services, to *parental training* courses for families and training professionals who act in this sector.

Chapter two intends to reflect on the paradigm of the quality of life referred to adult disability and the services referred to the caretaking of the persons with disabilities. To have a shared scientific setting of reference, we would like to start a first training proposal, which aims to acknowledge the *needs* connected with adult disability, especially in cases of autism and multiple disabilities, with an educational approach akin to the quality of life of persons with disabilities during their lives. Ultimately, the perspective is one of a long-term project. The common thread that links both training paths is the attention toward the person’s singularity, to his/her needs and the changes that he/she expects to happen over the time and therefore, the ability to plan and realise professional interventions for a full realisation of the quality of life. As we will indeed see later, despite what we said in chapter one on the great diffusion of the concept of quality of life in the field of vocational guidance, we need a careful professional training to pick the specificity of the educational practices in taking charge of persons with disabilities.

Although the discussion will focus on adult disability, we deem opportune to specify that this perspective should be thought and planned in a *continuum* during the course of life. Therefore, we will introduce some thoughts related to the quality of life of the adult person with disabilities. After the analysis of some essential *needs* of the person, we will address some important reflections concerning the educational practices of planning and caregiving of adult persons with disabilities.

Chapter three proposes a brief reflection on the possible directions in the life of a person with disabilities. It is based on the acknowledgment that the future of the disabled children, especially after the death of the parents, is a huge concern. The disabled person has to be prepared for what is called the “After Us”. The chapter defends the idea that the person with should be prepared disabilities and the family to the concrete possibility of autonomous life, even in a structure suited to the needs of the family member. To work within the paradigm of the Quality of Life, we need to find the life path of the person with disabilities taking into account occupation, training opportunities also at university level, internship, working insertion and protected workplaces, as well as residence and integrated networks in the community.

Finally, chapter four highlights the historical relationship between needs and assistance, especially since the post war Europe that built the welfare state model. This discussion opens the way to examine practical experiences from Italy and Brazil on educational and labour inclusion. The examples, which show big differences between the two countries are used to discuss the central place that work occupies in the people’s lives. This becomes even truer in the case of disabled people, for whom work is a possibility, or an instrument, of emancipation. An effective path of working inclusion leads to improve the Quality of Life of the person.

We hope you will enjoy reading this book and that it may bring fresh insights to help your work or to concern your world, in accordance with reason that brought you to read it. The Quality of Life is important to everyone and we hope that this book may help in building bridges between educators and disabled people, as well as other health professionals and people who have interest in this important subject.

Chapter One:
New horizons to plan inclusion

Di Catia Giaconi, Aldo Caldarelli, Simone A. Capellini

Preview

This chapter seeks an analytical reflection on different perspectives that can support the necessity to have sustainable proposals to initiate new forms of inclusive planning for disabled adults. Adult age disability creates new educational challenges, it demands a rethinking of the services provided for people with disability within the scope of the Quality of Life.

As authors and researchers of special pedagogy, we consider our focus to be the creation of the concept of *Quality of Life* (QOL), which will be explored in this chapter and will demonstrate its conceptual and professional potentials; including the field of special education and perhaps more relevantly, the scenario of the pedagogy of inclusion.

The philosophical medical and economic considerations on this subject will be examined in a multi-disciplinary analysis only within the scope of the attempts of conceptualisation and appreciation of the quality of life for disabled persons. Remarkable reflections and pedagogical implications arise from taking care of adult disabled persons. They range from organising daytime and residential services, to *parental training* courses for families and training professionals who act in this sector.

Within special pedagogy, this reflection becomes remarkably important to loosen old and new research boundaries, which, in the perspective of inclusion, tend to plan and realise new educational actions to improve the quality of life of disabled persons.

The framework of Quality of Life in the international consensus

The Quality of Life is a complex concept that brings interesting disciplinary approaches. To extricate ourselves among multiple studies, we deemed useful to begin with those international sources that have attained a general consensus on the main questions on conceptualising, measuring and applying the creation of the *Quality of Life* (QOL) for persons with disabilities. *Conceptualization, Measurement, and Application of Quality of Life for Persons With Intellectual Disabilities: Report of an International Panel of Experts* (Schalock *et al*., 2002), produced by an international group looking at quality of life (*Special Interest Research Group of Life* - IASSID), offers to the scholars the right coordinates to move in balance among many different definitions.

For the general question of quality of life, the *Handbooks* of high scientific and international level are equally important, among them are, *Handbooks on Quality of Life for Human Service Practitioners* (Schalock, 2002); *International Handbooks of Applied Research in Intellectual Disabilities* (Emerson, Hatton, Thompson, Parmenter, 2004); *Quality of Life and Disability: An Approach for Community Practitioners* (Brown, Brown, 2009).

There are also books series such as *International Handbooks of Quality of Life, Applying Quality of Life Research, Community Quality of Life Indicator* published by Springer.

Among the journals, we advise *Quality of life Research* edited by D. Revicki and C. Schwartz and *Applied Research in Quality of Life* edited by Shek or the *Journal of Intellectual Disability Research* for all that concerns the attempts of conceptualization, operation and research, in the educational field too.

Apart from these short notes, which will be amply referred in the bibliography, we would like to highlight that the *consensus* rests on a wide survey of the international scientific literature on the subject and on various meta-analyses carried out by several authors. They concern both the definition (Cummins, 1997a, 1997b; Felce and Perry, 1996; Hughes and Hawang, 1996; Schalock, 1996b, 2000b), and the aspects of measurement and application (Townsend-White, Pham, Vassos 2011). We extended the research on the theoretical level taking into account articles published after 2007, the cornerstone of previous meta-analysis and handbook references.

In Italy, the translation of *Handbook on quality for life for human service practitioners* (Schalock, Miguel, Alonso, 2006) represented a noteworthy contribution. It shows interesting integrations of the research on quality of life in different fields like special education, physical and mental health, intellective disabilities, old age and quality of life in the family.

At international level, many aspects became sharable thanks to the works mentioned above. Three 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.

We focus on these essential conceptual constructions, with relative changes, in the application and evaluation of the quality of life for persons with disabilities and the quality of the programs and services for taking charge of persons with disabilities.

Some authors (Felce, Perry, 1995; Schalock, Alonso, 2006) highlight the plurality of the definitions of quality of life in scientific literature as we put beforehand. The *trait d'union* comes from the scholarly awareness of the complexity and multi-dimensionality of the conceptual dimension of the quality of life.

In fact, researchers believe that quality of life as a multi-dimensional phenomenon is made by basic domains, e.g., a "number of factors that make the well-being of a person" (Schalock, Miguel, Alonso, 2006, p. 56). Leaving behind mere abstract definitions, to activate and "measure" quality of life, we identify some indicators within each domain of QOL, defined as "specific perceptions, behaviours or conditions for the domains of QOL that reflect the person's real or perceived quality of life" (*Abide*. p.67).

On this scientific line, we see how the incidence of personal and environmental factors on quality of life is measured. The consensus on domains and crucial indicators allows overcoming the classic debate on 'subjectivity-objectivity', which concerned which dimension to include or leave out in conceptualising QOL. For example, they include, health, residential and economic conditions, school integration, employment opportunities and community services offered (objective factors), or the psychological well-being and the subjective satisfaction (subjective factors). Broadly speaking, to reduce the contraposition, we use a common example: many people could be in excellent health for the objective criteria of their doctor, however, they may "feel" and perceive themselves in not good health. In other words, there is a dissonance between objective *standards* and subjective indicators. Let us focus on our scope, which is the quality of life for people with disabilities or persons who were diagnosed a psychopathologic disorder by specialised and multi-disciplinary *équipes*. This allows us to further explicit the thin border that separates objective and subjective dimensions. Persons with psychopathologic affections may subjectively perceive a certain degree of well-being, present issues that could undermine the adaptation to their context and individual quality of life; alternatively, they may distort completely the personal appraisal and interaction with the surrounding environment. Disabled people could instead undervalue some life goals like autonomy because they think that they are unable to attain them, or, they could accept modest life conditions because they became aware that, in comparison with previous stages of their lives, they could not expect any more than those levels (Caver, 2000).

The views of Orley, Kuyken (1994) and Wehmeyer, Schwartz (1998) help showing that these dimensions must be correlated through different mediation variables, also when "it is principally the perception of the individuals that is reflected on the life of the people" (Schalock, Miguel, Alonso, 2006, p. 61). Moreover, scholars like Edgerton (1996), Parmenter and Donelly (1997), among other researchers, showed that often the relation between subjective and objective indicators of quality of life is not only highly variable but also little practised.

International research often cites the domains of quality of life found by Schalock (Alonso and Schalock, 2002, Schalock, Gardner e Bradley, 2007), as we will see in the next paragraph, they concern emotional well-being, inter-personal relations, material well-being, personal development, self-determination, social inclusion and rights.

International guidelines consider the domains, regardless of their number, applicable to everybody and therefore, in our concern, to people with disabilities (Reiter & Schalock, 2008; Schalock *et al*, 2002). The basic domains are the same for everybody, even if the "content" may vary individually in terms of values and importance. Therefore, it remains an undisputable fact that these domains obtain different evaluations by the single objects; likewise, the value attributed to them changes during the course of life (Campo, Sharpton, Thompson, and Sexton, 1997; Schalock, Miguel, Alonso, 2006, p.48). Experiences have relevant role, different "systems" and contexts that influence our lives are shared in the same fashion (Petry, Maes and Viaskamp, 2005, 2007, 2009; Schalock, Keith, Verdugo, Gómez 2011; Schalock, Alonso, 2002).

After these premises, we analyse the other two important schools of thinking of the interpretation of the concept of quality of life.

Quality of life is susceptible to a temporal dimension, because, along with its perception, it changes potentially in a vertical direction in the different “stages” of life and, horizontally, in the different spaces of the person.

Furthermore, quality of life is open to multi-systemic reading. This *framework* is explained with the ecological dimension of the quality of life, especially on three levels that concern QOL of a subject and a disabled person directly. The micro-system is intended as the social environment that affects the person; the meso-system (neighbourhood, community, services and organisations) affects the micro-system directly; the macro-system directly acts on values, on the basis and meaning of the construction of QOL.

Therefore, to understand the quality of life of a person with disabilities is important to take into 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).

In the same ecological view, it is noteworthy to see that the perspective of QOL is directly linked and applicable to a micro level, in other words to personal growth and development opportunities, through meaningful potential perspectives of integration, equality, choice and self-determination (Wehmeyer, Schalock, 2001; Wehmeyer, Schwartz, 1998). This is becoming a central guideline in services to the person and in supplying benefits. Therefore, the person with disabilities and the surrounding context must be considered, intervening simultaneously on strengthening the context and the person (in self-determination, autonomy and more) to allow 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 (Nota and Soresi, 2002); affecting the social policies. Furthermore, it is possible to highlight that quality of life could take different forms in the three systems; to be supported by policies, like in Italy, aimed to promoting inclusion. However, these policies may not find adequate measures and integrated procedures to support the inclusion of the disabled person over time, therefore in a longitudinal planning perspective of quality of life of the people with disabilities.

This contribution adopts this conceptual scenario, with special reference to the conceptualisation and operation of this construction for disabled adults. It focuses on personal competence (Heal, Khoju and Rush, 1997, Heal, Khoju, Rush and Harnisch, 1999), but also on the relationships among people and their surrounding contexts (Brown, 1988, Felce and Perry, 1995, Goode, 1994, Keith and Schalock, 2000; Velde, 1997, Verdugo, 1995, Vreeke, Janssen, Resnick and Stolk, 1997).

We take into consideration those studies that may suggest interesting reflections in the context of our examination and that we will see mostly applied to the analysis of the quality of life of the people with disabilities.

We synthesise in few points what we have shared about the construction of the quality of life. Which are:

1. Multidimensional;
2. Made of domains and their indicators;
3. Influenced by individual and contextualised factors;
4. Inclusive of subjective and objective components, aware that individual perception of is the element that mostly reflects on their lives;
5. Based on needs, choices and individual control;
6. Applicable to everyone, even persons with disabilities;
7. Differently evaluated, from person to person, and in the different coordinates of space and time experienced by the subject;
8. To be taken in consideration at micro-, meso-, and macro-systemic levels, therefore in an ecological perspective.

Overview of the conceptual pictures

We will illustrate some proposals of conceptualisation of quality of life in this paragraph; they have been used in several researches on people with disabilities or psychopathological disorders.

The setting of the studies and research offered some conceptual pictures and effective models (Giaconi, 2014).

Starting from an analysis of the international studies, Soresi (Nota, Soresi, 2002; Soresi, 2006) finds the following dimension as the most recurring in the quality of life:

- Psychological well-being and personal satisfaction;
- Effectively lived social relations;
- Have a job;
- Physical and material welfare;
- Self-determination, autonomy and choice;
- Personal competence, social adaptation and the possibility of an independent life;
- Integration in the community;
- Social acceptation and status, adaptation;
- Personal development and realisation;
- Residential quality;
- Free time;
- Normalisation;
- Some demographical, social and individual aspects;
- Responsibility;
- Support coming from the services.

The implementation of such conceptualisations marked the passage from models based on the subjective and objective dimension to multi-dimensional ones. The latter articulate between the finding of dimensions observed in their interaction and the finding of various transversal factors where to look to evaluate the different dimensions. This is the case of the 3Bs by Renwick e Brown (1996). We propose a synthetic overview in table 3 "Conceptual pictures of QOL".

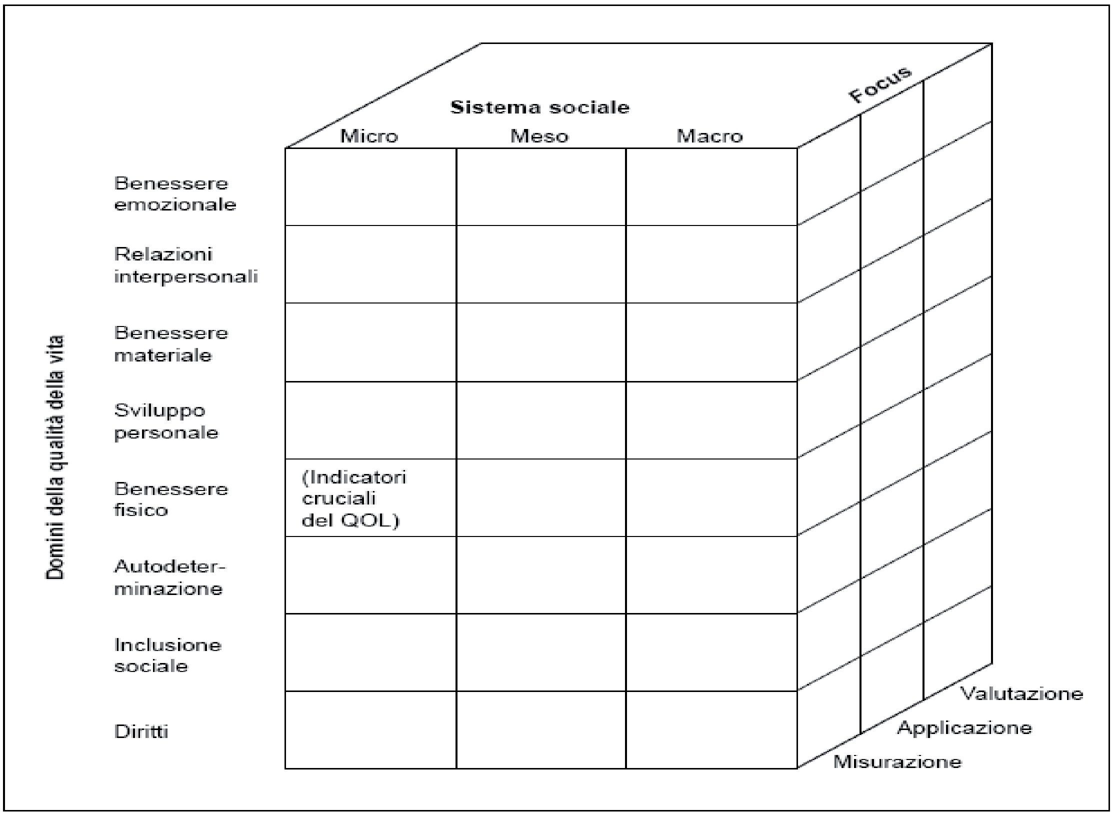
Remarkably, the late Nineties saw a surge of proposals of synthesis between the objective and subjective dimensions of the quality of life. For example, Brown (1989) considers as part of the objective dimension, the characteristics of the physical context, real support and stability of family relations. The same applies to the development of personal skills; the level of physical and social integration and the quality of the *training* and real support; the economic (income), health and food situations, as well as the philosophy of the services, the *équipe*'s attitude and the community. For the subjective side, the author emphasises how support, 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.

Moving to the most frequently quoted conceptual picture; we introduce the multi-dimensional proposal. At the beginning of the Nineties, during the *American Association on Mental Retardation* congress, Schalock proposed the "model" that eventually will become the most used in conceptualising quality of life; this includes the studies in the field of special pedagogy. The author presents eight crucial domains of the concept of quality of life (Alonso and Schalock, 2002, Schalock, Gardner and Bradley, 2007):

- Emotional well-being;
- Interpersonal relations;
- Material well-being;
- Personal development;
- Physical well-being;
- Self-determination;
- Social inclusion;
- Rights.

Below we reproduce the graphic (Tab. 1 – *Domains and heuristic perspective*) used by the author to define his "heuristic model". He does not only establish the domains in quality of life, but puts them on three different levels or systems: *micro* (a close context, next to the person), *meso* (community and services delivered) and *macro* (social policies). The heuristic model allows viewing the measuring, applying and evaluating *focuses* in quality of life.

Tab. 1 – *Domains and heuristic perspective*



Source: Schalock, Verdugo Alonso 2006, p. 66.

To access these *focuses*, Schalock *et al.* implement the concept of quality of life in domains turning them into indicators; their application and evaluation should reflect the personal results (Schalock, Gardner, Bradley, 2007) and the evaluation of the programs of the services delivered to disabled people. For example, the indicators of integration and participation to the community are considered to establish the social inclusion in the case of people with disabilities: for physical well-being, the indicators of health and free time; for self-determination, indicators of choices, autonomy and personal control. We introduce an explanatory table, which also refers to recent studies (Verdugo *et al.* 2013, 2014); it examines domains and indicators that arise from the analysis of theories and research (Tab. 2 – *Example of domains and indicators*). We introduce now domains and indicators in hierarchical order as emerged during investigation on people with disabilities (Schalock, Verdugo, 2006). A further operation to render the descriptors of the indicators is needed for the application that is observable in behaviour/situations.

Tab. 2 – *Example of domains and indicators0*

Domains	**Indicators**
Social inclusion	Integration and participation in the community, assistance
Physical well-being	Food, personal hygiene, medical care, health, health system, free time, sexuality
Interpersonal relations	Familial and social relations, communication
Material well-being	Possessions, durable goods, occupation, financial situation
Emotional well-being	Satisfaction, self-appraisal
Self-determination	Personal opinions and preferences, decisions and choice, personal control
Personal development	Personal wealth, learning, skills, motivation
Rights	Rights awareness, intimacy, *privacy*, discretion, respect

Concerning transversal perspectives, we deem important to highlight the proposal by Renwick, Brown (1996), as the project of the University of Toronto is often adopted, at European level, in the scope of quality of life also by associations and organisations that operate with adults in the autistic spectrum. Quality of life is defined as the degree of satisfaction through which people have access to possibilities and chances that they consider important for their lives (Brown *et al.*, 1997). The authors develop the construction of the quality of life in three transversal macro-areas: being, belonging and becoming which show the individual and specific characteristics of a person (being), the adaptation and quality of integration in the surrounding contexts (belonging), the planning and development in a person's space of life (becoming). This last dimension must be considered to exemplify crosscutting areas, domains and indicators. The macro-area of the becoming is explained at practical, recreational and evolutional level. For example, the practical aspect takes in account indicators like home, school and work activities; the recreation, activities and resources for the free time; the evolutional, lifelong learning and the capacity of learning skills to improve relations in life and adapt to new environments and situations.

Tab. 3 – *QOL's conceptual pictures*

Proposal	**Authors of Reference**
Integrant proposal: objective and subjective aspects in the quality of life	
Objective aspects: developing skills Characteristics of the physical environment Level of physical and social integration Quality and quantity of the *trainings* Real systems of support Income Quality of food Health Philosophy of services delivered Attitude of the *équipe* Attitude of the community Stability in familial relationships **Subjective aspects:** Increase and perception of self-control Security Social involvement and feeling of belonging Responsibility Autonomy Expectations Goals perceived as attained Perceived support Level of satisfaction Perception of personal health Normalisation	Brown *et al*., 1989
Multi-dimensional proposals	
Emotional well-being	Schalock (1996b, 2000)

Interpersonal relations Material well-being Personal development Physical well-being Self-determination Social inclusion Rights	
Proposals with cross-cutting dimensions	
Being Belonging Becoming	Renwick, Brown (1996)
Centrality Control Continuity	Cottini, Fedeli (2007)

The table clearly shows that over time the attention turned to integrate quality of life’s objective and subjective aspects, but also endeavoured to articulate conceptualising and applicative proposals along crosscutting dimensions, within which are evaluating domains and sub-domains of the quality of life. For example, we can think of the 3C perspective (Cottini, Fedeli, 2007), we share with the authors the perspective of their thinking in the analysis of the quality of life for people with disabilities. In fact, we believe that it is interesting to assess the indicators of quality of life in a disabled adult (like housing conditions, work integration and more). In other words, determining if the person has or uses them, to evaluate whether these indicators are central for the disabled person if the subjects can control them and whether these indicators possess temporal continuity. Temporal and planning dimensions are central in the perspective of the quality of life for people with or without disabilities, as we will show in chapter two.

The state of the art in international research

For some authors (Keith e Schalock, 2000; Mitchell e Winslade, 1997), the integrant systemic perspective in the field of disabilities opens an interesting path toward new research, which is also sustainable in terms of costs. In fact, as Schalock and Verdugo Alonso (2006) note, assuming that it is an integrant background at planning level, while taking charge of a disabled person; the ecologic dimension (micro-system, meso-system, macro-system) allows concentrating on the needs of people in their living contexts and the promotion of more efficient and effective supporting strategies.

In the perspective of services provided to people with disabilities, such a concept is invested with innovating and transforming power, let us remember that its multi-dimensionality includes the same components or domains for people with or without disabilities (Felce and Perry, 1997, Goode, Keith, Hoffman and Karan, 1989). Pointedly, it has been proved that the characteristics that belong to different groups can apply to disabled people too (Dennis, Williams, Giangreco and Cloninger, 1993).

Some aspects that have stringently to do with the quality of life of a disabled person must surely be remembered, they may concern health conditions and cognitive development (Borthwick-Duffy, 1992, Flanagan, 1976), the kind of disability, with possible cases of multiple disabilities and the age of the person (R.I. Brown, 1988). Furthermore, QOL is not fixed in time (Brown, 1998, Timmons and Brown, 19979) as it covers the entire lifetime.

In the joint analysis of the constructs “disability and quality of life”, we can find different perspectives of analysis and research.

Taking the international perspectives into account (Brown *et al.*, 2009), we can find three different reading options: firstly, the sensitising concept; secondly, the organising concept; thirdly the evaluating aspect of services and educational practices.

The concept of QOL has surely influenced research and social policies in favour the quality of life of all people and the people with disabilities (Brown, Bayer & McFarlane, 1989). It also applies to the levels of organisational planning, implementation of *training* and support, and finally, at evaluative level. QOL becomes a reference in the practices of evaluation of the programs personal development, in improving the quality of life for disabled people who tend to focus increasingly on the QOL *outcomes* (Schalock *et al.*, 2007).

Since the end of the Eighties until the beginning of the Two thousands we can find several authors who apply QOL to the field of intellective disability, like Brown (1988,1997), Cummins (1993, 1996, 1997), Goode (1988, 1994), Heal *et al.* (1985, 1995, 1997, 1999), Felce and Perry (1995, 1996, 1997), Schalock (1990, 1996b, 1997), Keith and Schalock (2000). Research extends also to people with multiple and severe disabilities – we refer to Petry *et al.* (2001) – and with the Autistic Spectrum (Giaconi, 2015). There are also references and studies in the fields of physical disabilities, psychopathological disorders (Schalock e Verdugo Alonso, 2006) and old-age disabilities (*Idem*; Cottini, 2008).

The abovementioned studies showed the potency of the multi-dimensional aspect of the QOL's concept.

Verri and others (1999) start from an Italian-Australian study carried out on a group of mentally retarded persons and on a group of people without mental retardation, they show that indicators of QOL in the evaluations of the two groups have no great differences.

In particular, in the national and international context, Schalock and Verdugo Alonso (2006) introduced a number of studies on intellectual disability and their heuristic model (*Abide*. p.155). Based on studies, research and articles analysis, the authors signal which ones – among the eight models of quality of life – are considered the most relevant in the life of people with disabilities. In the scope of this study the domains of social inclusion, interpersonal relations, self-determination, material well-being, emotional well-being and to a lesser extent personal development and rights result as the most explored ones (*Ibidem.* p. 162).

A large number of studies in the fields of quality of life and disability focus on the improvement of the quality of life of the subjects following de-institutionalisation and integration in the community. Studies by Wolfensberger (1972) record a poor quality of life for people who reside in institutions. In the same direction, starting from a review on studies about de-institutionalisation, Hatton (1996) emphasise a better quality of life for disabled people using the residential services of the community. This improvement should be linked to a higher participation of subjects 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.

Many studies explored the quality of life of people with disability in different types of residential services (Bellamy, Newton, LeBaron and Horner, 1990; Burchard, Hasazi, Gordon and Yoe, 1991; Howe, Horner and Newton, 1998). For this studies the best results occur in less protected structures, community ones, and in accord to the kind of intervention on the person with disability, in line with what we will reiterate on a desirable rehabilitation approach based on the community (CBR) and the Convention on the Rights of Persons with Disabilities (Caldin, 2014).

In implementing these positions, we find, comparing previous research, the studies of the longitudinal type on the significance of de-institutionalisation on the quality of life for persons with disabilities (Brown 2000, Hatton, Emerson, Roberston, Henderson and Cooper 1995, Lord and Pedlar 1991, Schalock and Genung 1993). They stress that the changes in the quality of life of people are in any case due to programs aimed to strengthen the competences of the persons and the capacity of being independent within a social group.

In the study by Schalock and Verdugo Alonso (2006) integration in the community, or the participation to its daily life, emerge among the indicators of the domain of social inclusion that occurs more frequently in scientific research and studies.

Another recurring domain is physical well-being, which is associated to indicators like health (often intended as physical assuredness), free time and daily life activities (Rapley and Hopgood, 1997). For the domain of interpersonal relations, recurring indicators are social and familial relations. We record instead important absences concerning the indicators of affective relationships (Schalock, Verdugo Alonso, 2006, p. 164).

For this purpose, we are especially interested in the domain of self-determination, it has relevance in the quality of life of persons with disabilities, and, it is interpreted as personal independence, choice, self and environmental control (Wehmeyer and Schalock, 2001, Wehmeyer and Schwartz, 1998). Several studies take this direction: Wehmeyer and others (1995) record higher self-determination in persons who live alone or in the family, as opposed to the ones in protective and restricted environments (Stancliffe and Wehmeyer, 1995) with a high levels of surveillance or in small family-groups. Stancliffe and others (2000) shed light on the fact that self-determination is higher in persons who live in environments with less than five individuals; it becomes significantly lower when the number of persons varies between six and sixteen.

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 (*Idem*). Furthermore, several authors consider self-determination a good indicator of the effectiveness of the treatments (Wehmeyer, 1998, Felce and Perry, 1995, Felce, 1997). It becomes necessary to strengthen integrating skills, the skills needed for participation and self-determination (Rusche *et al*., 1995; Nota e Soresi, 1997; Soresi e Nota, 2001). Furthermore, several studies stress that levels of self-determination in persons with intellectual disabilities are higher than what parents and operators perceive (Benz, Mc-Allister, 1990; Parson *et al*., 1990).

The domain of material well-being stresses the indicators of occupation and productivity. Specifically, several studies on disability, quality of life and occupation show improvements in quality of life (MacCraughrin, 1993) and higher satisfaction whenever we find a situation of structurally supported work rather than protected workplaces (Eggelton, Robertson, Ryan, Kober, 1999; Wehmeyer, 1994). To stay in the scope of works oriented to establish the factors that can improve the quality of life of persons with disabilities. 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 (Reiter *et al*., 1985; Wehmeyer, Bolding, 1999).

In the domains of emotional well-being, satisfaction and contentment result the most considered indicators; the domains of personal development and rights appear to be secondary, although they are always recognised as domains of quality of life also for people with disabilities (Schalock and Verdugo Alonso, 2016, p.167).

We concentrated this analytic section on the eight internationally recognised domains, because they are, among other things, as we are to see in the next paragraph, the guidelines to the various applications of the results of the international research. The latter considers two essential aspects that concern the evaluation of the quality of life of people with disabilities. Firstly, the evaluation is always linked with the QOL of all people in their surrounding contexts. Secondly, the evaluation of QOL in people with intellectual disabilities and psychopathologies should request validation by the persons who are significant for the subject and, anyway, as for the general research on QOL, they should include a triangulation of the research methodologies. The next paragraph will explore these aspects.

Quality of life for persons with intellectual disabilities: criteria and research methods

Research on the quality of life of people presents us with a rich and diversified series of tools of evaluation, and often of measurement.

These measuring procedures rest on the multi-dimensional models of QOL illustrated in the previous chapter. They include items that focus, in various forms, on social inclusion, interpersonal relations, self-determination, material welfare, physical welfare, personal development, emotional welfare and rights. Attention and scientific credibility are recognised for detection procedures that possess sufficient psychometric requirements (Borthwick-Duffy, 1992, Landesman, 1986). In this field, the prevalent methodologies are quantitative, while qualitative procedures, although getting more recognition over time including in QOL, continue to remain rather limited (Schalock and Verdugo Alonso, 2006, p. 247).

International *consensus* in researching QOL relies on fruitful integrations of quantitative and qualitative adjusting them according to the objective and subjective principles (Bertelli *et al.*, 2006; Heal, Sigelman, 1996). The integrated use of *reports* and *self-reports* represents a good validating example (Beadle-Brown, Murphy, DiTerlizzi, 2009; Schalock *et al.*, 2002; van Loon, van Hove, Schalock, Claes, 2008; Verdugo Alonso *et al.*, 2013).

In considering the methodological aspects of the QOL evaluation, two types of issues stick out. The first one concerns the “objective detection” (Schalock and Verdugo Alonso, 2006, p. 249) of indicators related to the domain of self-perception referred to the personal condition. The second problem concerns our scope: the research on the quality of life of persons with disabilities. In the case of persons with intellectual disabilities, the main difficulties lie in those studies that investigate the level of satisfaction reported the subjects about their quality of life (Sigelman *et al.*, 1980; Verri *et al.*, 1999).

Scientific literature highlights that persons with intellectual disabilities tend to report levels of satisfaction even when living in disadvantaged environments. According to some scholars (Heal and Chadsey-Ruch, 1985), the explanation lies in the low expectations from life of people with disabilities. The different life experiences of the persons with disabilities may cause a situation that drags down the expectations about the levels of quality of life (Carver, 2000). This effect brings the persons to be happy even in unsatisfactory situations, because they consider themselves unworthy of more or because they believe that the quality of present conditions compare higher to previous life experiences.

Despite the acknowledged need to evaluate subjective factors, especially satisfactions, only few studies have been carried out interviewing persons with intellectual disabilities. Those who made a similar attempt, worked with people able to answer the questions. Brown (1989), Parmenter (1987), Schalock (1990, 1991) 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.

Specifically, studies on the evaluation of quality of life in persons with disabilities show a number of methodological limits and difficulties. Authors like Sigelman, Budd, Spanhel, Schoenrock (1981) emphasise that persons with intellectual disabilities have difficulties to answer questions of the Yes/No, multiple and fill up types. They have problems also to choose missing pictures that show different aspects of the quality of their lives. Taylor and Bogdan (1996) affirm that the understanding of the subjective experience of the persons with severe disabilities is a foremost methodological challenge. Verdugo and others (2005) advise to encourage forms of *self-report* by simplifying the questions, but also to use alternative and augmentative devices of communication. The accessibility of these forms of self-evaluation remains linked to the presence of multiple disabilities and functional communication (Nota *et al*., 2007).

This is why some researchers like Cummins (1992), Vos, de Cock, Petry, Van den Noortgate, Maes (2010), Wong, Schalock and Chou (2011), Sines, Hogard and Ellis (2012), tend to involve family members and caregivers who live next to the disabled persons.

Studies that analyse critically this perspective are not in short supply, they signal the need for further research to validate and credit scientifically the statements coming from other persons like family members, professionals and caregivers (McVilly and Rawlinson, 1998). Concerning the procedures to interview persons with intellectual disabilities, Stancliffe and others (1995) highlight that the subjects tend to answer positively or in a stereotyped manner to the interviewers.

Consequently, in investigations that interview intellectually disabled persons, researchers should consider the distortions contained in the answers (Heal, Sigelman 1996) and the differences in perception that occur between the disabled person and the family members, or the “key informants". The latter are the family members and the personnel in the structures caring for disabled persons (Barry *et al.*, 1997; Becker *et al.*, 1993). The investigation should declare when information come from a third party and not the investigated person (Verdugo *et al.*, 2005). Also in analysis that include self-reporting and reporting is advisable to analyse separately the data in order to determine their degree of concordance (Verdugo *et al.*, 2005).

Therefore, researchers (Townsend-White, Phan and Vassos, 2012; Verdugo *et al.*, 2013) let the lack of proper and sufficiently reliable tools emerge for intellectual disabilities and, even more, for persons with severe disabilities, who are persons who may present multiple disabilities like a severe intellectual disability, but also motor dysfunctions, chronic and degenerative diseases, psychopathological and behavioural disorders.

We consider important the stress attributed to the degree of personal satisfaction and self-realisation of the subject with disabilities, as we will see it allows directing strategies and educational actions toward often-overlooked dimensions, like manageing free time and recreational activities.

In the light of the abovementioned, the most accepted research direction 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.

Procedures of evaluation and QOL in disabled persons

At this point of the narration, we deem important to provide the reader with an overview of the 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. Some scholars (Malm *et al.*, 1981; Katschning *et al.*, 1997; Placentino *et al.*, 2003) sustain that, regardless the concept of quality of life being considered essential in professional practices in taking care persons with disabilities and psychopathological disorders, the evaluating procedures appeared later than in other fields of medicine (Placentino *et al.*, 2003, p. 169).

At international level, the *Australian Centre on Quality of Life* describes approximately a thousand and two hundred tools with that have the goal to measure, in some way, the quality of life of the general population, or, within the health/medical context or in disabilities, to provide the dynamic perspective in the objective and subjective indicators of quality of life.

To direct the evaluation practices, scholars like Goode (1990), Dennis and others (1993), Schalock and Verdugo Alonso (2006) rightly signal three aspects that often recur in the international literature:

- Relevant factors to evaluate the QOL of the general population are applicable also for disabled persons;
- The evaluation of the QOL of persons with intellectual and psychopathological disabilities demands a validation from their proxies;
- The QOL of persons with disabilities relates to the quality of life of the other persons in the surrounding environment.

There is a remarkable attention in the studies on the quality of life toward children, adolescents, adults and older persons with intellectual disabilities (Schalock, Verdugo, 2002; Watson, Keith, 2002). For example, we would like to stress that among tools used to study QOL of adolescents with intellectual disabilities that the *Quality of Life Profile: Adolescent Versions* (QOLPAV; Meuleners, Lee, 2005; Raphael *et al.*, 1996) was applied also to students with intellectual disabilities. The *Quality of Life Questionnaire* (QOLQ, Keith, Schalock 1994,1995) was used by the same authors for groups of youngsters, with or without disabilities. *ECV* (measuring the quality of life of older persons with disabilities) investigates the perspective of disability associated to ageing; it illustrates some interesting Italian perspectives, like the models of multi-dimensional intervention for a life of quality (Cottini, 2008).

For orientation purposes, given the vast choice of purposes that periodically appear on the scientific scene, the systematic reviews of the measuring tools of the quality of life should include the field of disability (Schalock and Verdugo, 2002; Townsend-White, Pha, Vassos 2011).

We usually distinguish the generic instruments used to evaluate the quality of life by comparing groups, and specific procedures used for persons with specific disabilities or pathologies (Lera, 2005).

Schalock and Verdugo (2002) affirm that the most used procedures, including the field of intellectual disabilities, are the *Quality of Life Questionnaire* (QOL.Q; Schalock and Keith, 1990, 1993) and the *Comprehensive quality of Life Scale-Intellectual Disability* (ComQol-ID; Cummins 1991, 1993), both have good psychometric proprieties (Cummins 1993; Verdugo, Caballo, Prieto and Peláez, 2000).

The review by Townsend-White, Pha, Vassos (2011) on the examination of the tools excludes those that do not measure the eight key domains of the quality of life at international level, and also the procedures that demand an administration time of more than two hours and are planned and realised only to gather the so called proxy persons who know well the analysed subject (*Ibidem.* p. 273).

From the systematisation, we extracted the following tools.

1. *Choice Questionnaire* (Stancliffe, Parmenter, 1999);
2. *Comprehensive quality of Life Scale* (Com-QOL-I; Cummins, 1991);
3. *Consumer Satisfaction Survey* (Temple University, 1988);
4. *Evaluation of Quality of Life Instrument* (EQLI; Nota, Soresi and Perry, 2006);
5. *Guernsey Community Participation and Leisure Assessment* (GCPLA; Backer, 2000);
6. *Life Experiences Checklist* (Ager, Eglinton, 1989);
7. *Life Satisfaction Matrix* (Lyons 2005);
8. *Lifestyle Satisfaction Scale* (LSS; Heal e Chadsey-Rusch, 1985);
9. *Maryland Ask Me! Project* (Bonham *et al*., 2004);
10. *Mood, Interest and Pleasure Questionnaire* (Ross, Oliver, 2003);
11. *Multifaceted Life Satisfaction Scale* (MLSS; Harner, Heal, 1993);
12. *Overt Behaviour Scale* (Kelly *et al*., 2006);
13. *Personal Outcomes Measure* (Gardner *et al*., 1997);
14. *Personal Well-being Index* (PWI-ID; Cummins, Lau, 2005);
15. *Quality of Life Assessment Form* (McGuire *et al*., 1991);
16. *Quality of Life Assessment Tool* (Johnson, Cocks, 1989);
17. *Quality of Life, Enjoyment & Satisfaction Questionnaire* (Q-LES-Q; Endicott, 1993);

18. *Quality of Life Index* (Campo, Sharpton, Thompson e Sexton, 1996);
19. *Quality of Life Instrument* (Janssen *et al*., 1999);
20. *Quality of Life Instrument Package* (Raphael *et al*., 1999);
21. *Quality of Life Interview Schedule* (QUOLIS; Ouellette-Kuntz, 1990);
22. *Quality of Life Questionnaire* (Brown, Bayer, 1992);
23. *Quality of Life Questionnaire* (QOL-Q; Schalock, Keith 1993);
24. *Questionnaire on Quality of Life* (Cragg, Harrison, 1989).

After evaluating the lack of specific precautions for the evaluation of QOL for person with intellectual disabilities (*Ibidem.* p. 276), the authors selected six tools that satisfied the criteria of their studies and specifically correspond to the psychometric parameters. The six tools are:

1. *Multifaceted Life Satisfaction Scale* (MLSS; Harner, Heal, 1993);
2. *Comprehensive quality of Life Scale* (Com-QOL-ID; Cummins, 1997);
3. *Quality of Life Questionnaire* (QOL-Q; Schalock, Keith 1993).
4. *Personal Well-being Index* (PWI-ID; Cummins , Lau, 2005);
5. *Quality of Life Interview Schedule* (QUOLIS; Ouellette-Kuntz, 1990);
6. *Evaluation of Quality of Life Instrument* (EQLI; Nota, Soresi and Perry, 2006).

Beside the above, we need to deepen the *Quality of Life Instrument Package*, which was adapted to Italian in 2011 and possesses good characteristics of validity and reliability (Bertelli *et al*., 2011).

Verdugo, Gómez, Arias, Navas, Schalock (2014) strengthen the argument, an avenue opened by the work of Townsend-White, Pham, Vassos (2012), which analyses the evaluation of the multiple disabilities. The authors warn about the poor specificity of the tools that evaluate the quality of life of persons with multiple disabilities. It is interesting to deepen the proposal of these authors: the *Scale of San Martin* (Verdugo, Gómez, Arias, Navas, Schalock, 2013, 2014), which was recently translated in Italian and available on-line. In Italy, many studies are carried out "evaluating the quality of life in mentally retarded adult persons" (QdV-RM; Nota, Soresi, 2002).

It is important to review rapidly the nine tools that we will examine chronologically, according to the year of authorship:

1. *Quality of Life Interview Schedule* (QUOLIS; Ouellette-Kuntz, 1990);
2. *Multifaceted Life Satisfaction Scale* (MLSS; Harner, Heal, 1993);
3. *Quality of Life Questionnaire* (QOL-Q; Schalock, Keith 1993);
4. *Comprehensive quality of Life Scale* (Com-QOL-ID; Cummins, 1997);
5. *Quality of Life Instrument Package* (Raphael et al., 1999);
6. *Evaluation of the quality of life in mentally retarded adult persons* (QdV-RM; Nota, Soresi, 2002);
7. *Personal Well-being Index* (PWI-ID; Cummins , Lau, 2005);
8. *Evaluation of Quality of Life Instrument* (EQLI; Nota, Soresi e Perry, 2006);
9. *San Martin Scale* (Verdugo, Gómez, Arias, Navas, Schalock, 2013, 2014).

Quality of Life Interview Schedule (QUOLIS; Ouellette-Kuntz, 1990) is an instrument developed by Ouellette-Kuntz and considers twelve domains that involve health services, cases caring, means of transportation, the social recreational dimension, cultural and religious aspects, family protection, maintenance of income, supports, housing, security, *counselling* and *aesthetics*. Generally speaking, the twelve domains concern support, access, participation and satisfaction. The evaluation procedure includes *self-report* and *report* provided by the *proxies*, in case of serious disability, the interviewed were mostly brothers, family members and people close and meaningful in the life of the disabled persons.

The *Multifaceted Life Satisfaction Scale* (MLSS; Harner, Heal, 1993) considers six domains that relate to satisfaction within the community and interpersonal relations, friends and free time, services and employment. This procedure prescribes only the *self-report*.

Il *Quality of Life Questionnaire* (QOL-Q; Schalock, Keith 1993) evaluates general satisfaction, competence and productivity, *empowerment* and independence, belonging and integration in the community. Therefore, it concentrates on social inclusion, self-determination, material and emotional well-being. It was developed also for the proxies when the subjects are unable to answer.

The structure of the QOL-Q sheds light on the factors that more than others determine QOL and concern independence, productivity, and integration in the community, the satisfaction of personal needs and values and the "happiness that accompanies such satisfaction". The items of independence concern the personal possibility to exert control on the personal context and make choices; the items related to productivity refer to the opportunity to obtain positive results on the workplace (usefulness and income for the person, family and community); the items of integration in the community concern personal participation to a number of activities (working, social, interpersonal) that are usually carried out by non-disabled persons.

The *Comprehensive Quality of Life Scale* (Com-QOL-ID; Cummins, 1997) examines social inclusion, interpersonal relations, material, physical and emotional well-being. Cummins, in the 1997 manual, envisages this tool to respond to the multi-dimensional perspective and to evaluate both the objective and the subjective perspectives. The scale was initially named Com-QOL, then "Scale for the evaluation of the quality of life of adults", eventually planned by Cummins as Com-QOL-S to evaluate the quality of life of adolescent students and as Com-QOL-ID to measure the quality of life of persons with intellectual disabilities. This scale too, like the QOL for disabled persons, envisages the possibility to interview proxies of the persons examined. Com-QOL-ID includes the scale of reliability (for example, "Does the watch – or any other object that belongs to the person – belong to you?), the objective scale (for example, "Where do you live? In a house, apartment or room? Do you live in a rented or owned home? How many hours do you devote to the following activities? Do you always have something to do in your free time?), the subjective scale and the relative of importance/satisfaction (for example, "Are the things you do, your health, family and similar important for you?").

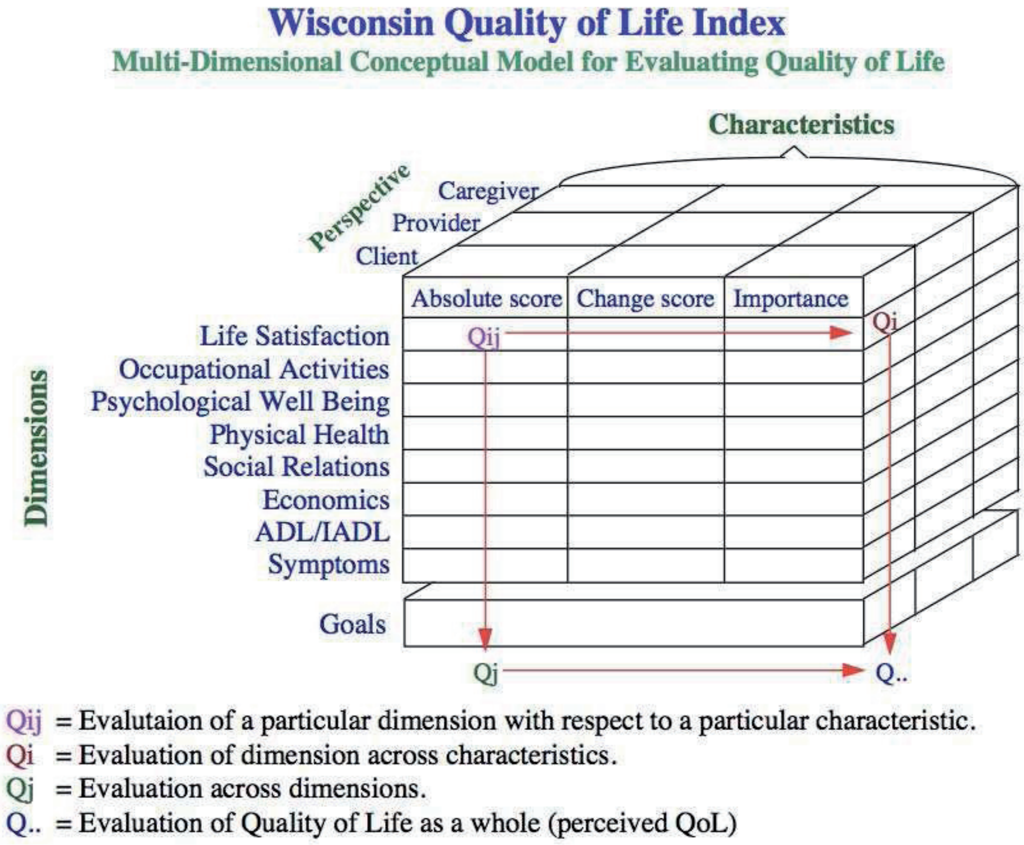
The *Quality of Life Instrument Package* (Raphael *et al.*, 1999) belongs to the perspective of importance/satisfaction. It allows assessing the tree macro-areas of "Being", "Belonging" and "Becoming", which assemble nine areas of QOL, they are rendered with six *items* per area in the questionnaire. The macro-dimension "Being" includes several aspects, physical (physical health, food, personal hygiene, psychological well-being among others), psychological (autonomy, acceptation, control of the stress among others), spiritual (values and beliefs), it allows describing the main characteristics of the person. The macro-area called "Belonging" is to be split in physical dimension (the place lived-in by the disabled person, safety at home, possession); social dimension (familial relations, belonging to social, cultural and interest groups); community (availability and access to resources and services, medical, educational, recreational and financial, offered by the community of reference). It allows appreciation of the relationship between the person and the surrounding environment. The "Becoming" applies to the practical (domestic, school, training and working activities), recreational (activities for fun and passion) and evolutional (adapting to life changes, maintaining and developing personal activities and interpersonal relations), it also allows the evaluation the planning and changing dimensions during the life of a person with disabilities. As it happens, in the Italian adaptation, seven out of nine areas are assessed by interest, satisfaction, decisional satisfaction and opportunities (Bertelli *et al.*, 2011, p. 208).

Cummins and Lau (2005) developed the *Personal Well-being Index* (PWI-ID), in elaborating this tool, the authors' perspective is that many quality of life evaluating procedures cannot make a clear distinction between subjective and objective dimension. They therefore propose an evaluation protocol of the subjective dimension of the quality of life that originate from abandoning the old *Comprehensive Quality of Life Scale* (ComQOL), due to various psychometric reasons, rightly highlighted by Cummins in his contributions in highlights rightly in his contributions of 2000 and 2002 (Cummins, Gullone, 2002). The person is invited to tell the level of satisfaction referred to various domains of the quality of life, which go from the standard of life and health to interpersonal relations, security, community connections and future perspectives of security. In this case too, there are parallel forms to evaluate QOL, for pre-school children (PWI-PS), adolescents (PWI-SC), adults (PWI-A) and persons with disabilities (PWI-ID).

Evaluation of Quality of Life Instrument (EQLI; Nota, Soresi e Perry, 2006) is a procedure to evaluate, by the personnel in service, the level of satisfaction of adults with intellectual disabilities who frequent residential and daytime structures. It is mainly an instrument of hetero-valuation. Caregivers of disabled persons evaluate the quality of life attended by the services. The professionals evaluate the satisfaction of the person with disabilities in relation to proposed activities and interventions. In other words, these are the opportunities to enjoy social integration, characteristics of the environments frequented by the subject (order, cleanliness and more). The perspective of the authors includes tools for QOL overall evaluation, QOL questionnaires for family members and QOL for caregivers.

Wisconsin Quality of Life Index (Beker *et al.*) includes a series of questionnaires addressed to adult and older persons with intellectual disabilities and psychopathological disorders and to their family members and professional agents. The tools can be used individually, however, in the view of the authors, as we can see below (*Tab.* 4), the evaluation is always the multi-dimensional perspective of QOL and a kind of “tri-dimensional” approach, which is the evaluation by the persons with disabilities, *providers* and *caregivers*. The evaluation regards the general level of satisfaction (referring to environment, housing, food, resources and services), degree of importance of each indicator, activities and occupations (daily activities, school, work, free time), psychological and physical well-being, support and social relations, economic situation (for instance, adequate income, control over financial resources and more), daily activities (for instance, independent meal cooking, personal hygiene among others), symptoms (like symptoms of the personal conditions influencing the quality of life and *personal functions* or if the persons is prone to forms of self-harm and aggression toward the others) and attainment of the goals (for instance: evaluation of the goals desired or reached with the treatment).

Table 4 – *Wisconsin Quality of Life Index*



Qij = Evalutaion of a particular dimension with respect to a particular characteristic.
Qi = Evaluation of dimension across characteristics.
Qj = Evaluation across dimensions.
Q.. = Evaluation of Quality of Life as a whole (perceived QoL)

Source: Beker et al.

Among the developments of the perspectives in the field of multiple disabilities, we find the *San Martin Scale* introduced by Schalock and Verdugo (2002). The authors developed this scale after having met with difficulties in finding evaluation procedures suitable to evaluate adult persons who ask for extensive and generalised assistance (for example, persons with multiple and severe disabilities). An external observer fills the scale, he/her knows the subject well, having more than three months experience; he/her has the opportunity to observe the subject in different contexts for sufficiently long periods (Verdugo *et al*., 2014). A thorough reading of the scientific literature brings Verdugo and others (2013, 2014) to find eight domains of QOL and their indicators, which we introduced in the paragraph "*Overview* of the conceptual pictures". The scale applies to the Spanish context, it was translated to Italian 2014; it focuses on the eight dimensions proposal by Schalock and Verdugo. It is made of ninety-five *items*, split among the eight domains of QOL, which resume the detectable and objective aspects that the observer places according to the frequency (never, sometimes, frequently, always) of appearance in the person with disabilities.

Here are some examples of *items* for self-determination: do the persons who look after you consider your preferences and choices? Do you participate to the elaboration of your program of individual assistance? Do the personnel respect your decisions? Do you choose how to spend your free time? Are specific steps adopted to allow independent choices? Concerning the aspect of emotional well-being: is the person informed in advance of possible changes of caregiving personnel (shifts, permits, holydays, and others)? Do the caregiving personnel know your personal expressions of emotional well-being? Do the caregivers know your expressions of anguish? Are specific measures adopted to make your environment recognisable and predictable (for instance, spaces, timetables, caregiving personnel, activities)? Physical well-being: do you follow a diet suitable to your characteristics and needs? Do you move in different spaces (outside and inside)? Are specific measures adopted in relation to your mobility to enhance your independence? Material well-being: are your personal belongings repaired or substituted when they deteriorate? Is the centre that you attend suitable to your characteristics (sensorial, cognitive, among others)? Do you have a physical space with your belongings at hand, do the caregivers know the alternative systems of communication that you need? Are specific measures adopted to adapt your living environment to your abilities and limits (sensorial, cognitive, and behavioural)? Rights: is your *privacy* respected in the centre that you attend (knocking the door, close the door for washing or changing diapers)? Is there, in the centre, a place where a person can stay alone if he/her desires so? Personal development: do your activities help to acquire new abilities? Do you learn things that make you more independent? Are specific measures adopted to acquire new abilities? Social inclusion: do you have chances to know environments other than the place where you receive services/assistance? Do you participate to activities of social inclusion suitable to your physical and mental conditions? Are specific measures adopted to increase your participation in the society? Interpersonal relations: do the caretaking persons know your system of communication? Are you allowed the necessary time to answer in interacting with the personnel? Are specific measures adopted to improve your communicative ability? Are specific measures adopted to maintain and extend your social relations? Excluding the various sections of data detection or further sensitive notes for evaluation, a profile of quality of life illustrates graphically the results of the evaluation, providing information suitable to elaborate personalised programs. As mentioned already, the *Scale of San Martin* showed scientific reliability and validity in the Spanish context (Verdugo *et al*., 2013), while we wait for studies in this field in the Italian context.

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.

Following this direction, finally, we deem important to report the guidelines accepted at international level:

- Evaluation of the degree in which people make significant life experiences to which they attribute value;
- Evaluation of the importance of the single contexts in making life full and rich of relations;
- Realising evaluations in the living contexts that are important for the person;
- Founding the evaluation on common human experiences and the ones that belong to single individuals;
- Having triangular procedures available as observers and tools of the Quality of Life of persons with disabilities (Giaconi, 2015).

Chapter Two:

Knowing adult disabilities to make inclusion

Di Catia Giaconi, Noemi Del Bianco

In this chapter, we intend to reflect on the paradigm of the quality of life referred to adult disability and the services referred to the caretaking of the persons with disabilities.

In particular, to have a shared scientific setting of reference, we would like to form a first training proposal, which aims to acknowledge the *needs* connected with adult disability, especially in cases of autism and multiple disabilities, with an educational approach akin to the quality of life of persons with disabilities during their lives. Ultimately, the perspective is one of a long-term project. The common thread that links both training paths is the attention toward the person's singularity, to his/her needs and the changes that he/she expects to happen over the time and therefore, the ability to plan and realise professional interventions for a full realisation of the quality of life. As we will indeed see later, despite what we said in chapter one on the great diffusion of the concept of quality of life, in the field of vocational guidance, we need a careful professional training to pick the specificity of the educational practices in taking charge of persons with disabilities.

Although the discussion will focus on adult disability, we deem opportune to specify that this perspective should be thought and planned in a *continuum* during the course of life. Other authors (Pavone, 2008) underlined that the project of life for persons with disabilities begins at birth and shapes continuously through the lifespan, accompanying the growth and life of the person with disabilities.

Therefore, we will introduce some thoughts related to the quality of life of the adult person with disabilities. After the analysis of some essential *needs* of the person, we will address some important reflections concerning the educational practices of planning and caregiving of adult persons with disabilities.

The essential *needs* of the adult person with disabilities

The international literature has showed long ago that not only the perspective of quality of life of persons with disabilities was seen only in one direction, but also most importantly, how long it took to be able to look at people with disabilities in longitudinal temporal perspective, hence through their lives. Notwithstanding that the significant increase in life expectancy has been long demonstrated thanks to medical, social (Ferris, Bramston, 1994) and recently by neuroscientific progress, the collective imagination continues to persists on the idea of the disabled person as the "eternal child".

The difficulties of the families of disabled subjects during the phases of transition complement the above. For example, from the time spent by the disabled in school contexts to the time expected to insert him/her in the various social contexts, including a high percentage of risk to remain at home with the parents whom, in older age, may not always be able to provide the right supports for a quality of life.

We must stress that an adult person with disabilities risks precocious ageing in terms of cognitive functions, besides natural ageing, 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 often accompanied by a rehabilitative void. Studies proved how the decline of the cognitive functions and those motor-perceptual or affective-relational are subject to different variables, which are not strictly due to ageing, which concern "cognitive level, lifestyles, experiences and other possible associated pathologies" (Cottini, 2008, p. 94); or to psychopathological disorders.

The above grows with ageing, the adult person with disabilities, after losing the network coming from the school contexts, loses the family's supporting network, because of the frail health or death of both parents. Here too, the phase of transition from the original home to the one of other family members (brothers, sisters) or, often, to residential structures is a complex passage, insufficiently prepared and scarcely respectful of the quality of life of persons with disabilities.

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. How can we guarantee quality of life to a person with disabilities?

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 will see this path is at its initial stages and it is not a sustainable solution for persons with intellectual disabilities. Here too, not all situations focus concretely on the concept of quality of life, since even cases where an adequate assistance is available, practices of maintenance and improvement of the quality of life remain only an abstraction.

We analyse the *needs* of persons with disabilities referred to the domains of quality of life that we exposed above, as speculative exercise, they are useful to make some reflections in a temporal and planned dimension. Specifically, we will analyse the eight domains introduced above (Schalock *et al.*, 2010) in the three large areas of independence, social participation and well-being. As seen before, independence includes the domains of personal development and self-determination; social participation counts on the dimensions of interpersonal relations, social inclusion and rights; well-being concerns the aspects of physical, material and emotional well-being.

We dwell on the domains that emerged from the examination of the literature, seeing what changed over time for a person with disabilities and what is needed to develop educational practices in a perspective of quality.

1.1 Independence: personal development and self-determination

Personal development is an important element for the quality of life of people. In relation to it, the perspectives of lifelong learning and of personal competences are essential indicators.

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, the activities should concern the mental age and the feasibility of an adult life project not the life of an "eternal child".

A rich literature (Cottini, 2008) underlines the perspective of intervention on the processes of decline in the persons with disabilities, for example, among persons with intellectual disabilities who can answer rapidly, who have visual-spatial, mnemonic, linguistic abilities, the control of executive processes over and the adaptive ability in their own community (*Ibidem.* p. 110). Decline is in any case slowed down in persons who continue to live in stimulating environments from the educational and skill-training viewpoint, since it does not depend strictly on age, but to variables like the severity of the condition or other pathologies.

International studies (Lachapelle, Wehmeyer *et al.*, 2005) demonstrated that self-determination is a crucial dimension to improve the quality of life and social inclusion. For the persons, in our case persons with disabilities, possessing a high level of self-determination increases the possibilities of having a positive adult life, e.g., in terms of work, autonomous and independent life. Therefore, the same level of satisfaction of life is strongly connected to the level of self-determination (Wehmeyer, 2009).

Which role has self-determination in the life of adults with disabilities, for example, in the case of a subject with intellectual disabilities living in a socio-educational centre or in an educational community? Is self-determination promoted or limited by the environments inside the contexts where persons with disabilities live, work, learn and interact?

Nota, Soresi and Wehmeyer (2007) evidenced that persons with severe intellectual disabilities have a lower level of self-determination, social skills and quality of life. In other similar studies, Wehmeyer (2010) proved that the self-determination is irrespective from the surrounding environmental conditions (*must*) and functional conditions. Therefore, self-determination should be promoted in all educational practices in giving care to persons with disabilities, regardless of available environmental situations and functional conditions.

For self-determination, we mean "acting as the main causal agent of our own lives, making choices and taking decisions regarding our own quality of life free from improper influences and interferences" (Wehmeyer 1996, 2002, 2009; Wehmeyer, Schalock, 2001). Self-determination is not linked to the ability of the persons to do thing autonomously – this aspect would be lacking in persons with severe disabilities – but is tightly connected to the decisional process (Wehmeyer, 2009). However, also in this direction, adult persons with disabilities find themselves in life contexts where the others (family members, caregivers) often choose in their place. These choose how to organise their time, what the subjects can or cannot do. Therefore, how can we also work for this goal with persons with disabilities?

Functionality is also needed in the domain of self-determination as well as finding the indicators of the same domain. It is necessary to explore this domain too, to find the elements that define it operationally. Wehmeyer and Schalock (2000) describe four essential characteristics in self-determined behaviour: autonomy, self-regulated behaviour, psychological *empowerment* and self-realisation (Wehmeyer, Schalock, 2001). We can analyse them in reference to the quality of life of persons with disabilities.

Autonomy belongs to the capacity of action of the person with disability referring to the system of personal preferences and interests, or, the ability of taking decisions and making choices. Do we see family members and caretakers near the person with disability who, besides working on his/her behalf in his/her interests and preferences, allow the person to act on the bases of his/her personal preferences and therefore construct occasions, opportunities and spaces for independent actions? Do persons with disabilities have, even if living in residential structures, during their daily programs the possibility to choose between two options, for example, in the activities to do? 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.

Self-regulated behaviour includes the ability of interpersonal *problem solving* and the perception of self-control. Are educational actions to promote *problem solving* abilities activated? Does the person have the opportunity of making experiences of control and choice? Are practices of intervention on the definition and attainment of real goals activated?

Psychological *empowerment* concerns the work on the levels of self-sufficiency and of an internal *locus of control*, while self-realisation relates to the degree of self-awareness and self-knowledge. Are there intentional actions directed to promote indicators of self-determined behaviour?

Following this direction, international research has promoted evaluative procedures of self-determination for persons with disabilities, as instruments of self and hetero-evaluation. We report, for example, the scales of evaluation of self-determination by Soresi and Nota (2007). The scale of evaluation examines self-determination in reference to the daily activities, for instance, the person with disabilities can choose how to spend the money, or to express his/her emotions, or be free to participate to the day's activities and make, usually, his/her own choice.

Specific programs were created to meet these guidelines (Field, Hoffman, 1996, 2002; Soresi *et al.*, 2009; Wehmeyer, Kelchner, 1997). The indications for intervention concern also some contextual changes such as the decreasing tendency toward hyper-protection and non-necessary caregiving interventions, while promoting the opportunities of choice. Environments that help self-determination contemplate also technological supports that facilitate expressing personal preferences (Robertson *et al.*, 2001).

In short, the vision of educational action cannot be restricted to concrete actions enhancing the quality of life; it must make sure that the person with disabilities gains significant levels of self-determination.

Social participation: interpersonal relations, inclusion and rights

We move now to the domain of social inclusion. Special pedagogy sees a meaningful value and a goal to attain in the social inclusion of disabled person. Over time, subjects with disabilities run the risk of having fewer and fewer opportunities of 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. International literature (Irvin, Close, Wells, 1987) has long been aware that the possibility to improve the quality of life of persons with disabilities connects strictly with the availability of services and *training* to enhance the *Daily living skills*. These are the functional skills of daily life (household activities and care), and the *Community living skills* intended as skills to live in the community (mobility within the community, access to services and money, social skills among others), considering the most functional skills of social integration (Ianes, 1984). We must also consider what the actual or potential living context expects from the subject in terms of adaptive behaviour (Brown, Leigh, 1987; Ianes, 1987; Scholoss, Scholoss, 1985). 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 for persons with disabilities and social inclusion, even when the level of adaptability is low. Therefore, the perspective is surely the one of individual empowerment; it also creates a supporting social network (Romer, Heller, 1983) for social inclusion.

We move now to the dimensions of *interpersonal relations* and personal development. Does the disabled person, even when living in a residential structure, keep the links with family members, relatives and friends? Does he/she frequent other structures in the community beside the day or residential centre? This is another reason why the intervention becomes significant, on one hand, it works on the subject to strengthen social skills and communicative forms, it tries to intervene in case of behavioural issues; on the other hand, it works on the rehabilitation and socio-educational context, which must be open to the subject's community of reference and belonging. Persons with disabilities must keep their social networks and be able to adopt forms of communication suitable to express themselves and enter into relationships. Caregivers must know these modalities to provide the right support over time. The level of quality of life of the persons with disabilities couples intimately with the ability of the subject to active intervention in interpersonal networks. Instead, the subject could be surrounded by a social network that takes no notice of his/her participation or interests, that makes choices for him/her, even when the structure provides high levels of service, will not improve his/her quality of life.

Within the dimension of *rights*, each one of us possesses the prerogative to have personal dignity respected, be a citizen and have full legal protection. Operationally, this perspective means having a personal space of *privacy*, having access to community structures and free time. It is noteworthy observing the different way structures for persons with disabilities are organised: to understand if the services respect the *privacy* of their guests if the structure has private rooms to be personalised with objects and photos that can provide the sense of history, present and future of the person with disabilities.

Well-being

We examine now physical, material and emotional well-being.

The aspect of physical well-being could be satisfied by the structure of family support or by the residential or semi-residential structure, which provides appropriate food standards, care of personal hygiene, proper medical care. An interesting indicator to establish the material well-being of the person regards the management of the free time. In fact, free time and recreational activities are two areas frequently and highly disregarded when taking charge of the person with disabilities (Janssen *et al.*, 2005). The trend is to make recreational proposals and activities consecrated exclusively to disabled people, which feed further separation from the community of belonging or the simple insertion if not active participation. Free time and contact with non-disabled persons influence positively the quality of life of adults with disabilities (Dagnan *et al.*, 1998).

Several studies (McConkey *et al.*, 1981; Sturmey, 1995) highlight the risk for adult persons to spend most of their free time at home and to spend it alone or with the family members. Investigations by ISTAT (Italian National Institute for Statistics) on the diffusion of satisfaction in the various aspects of daily life, confirmed that persons with disabilities consider themselves very or sufficiently happy of their familial relationships, while the percentage of those happy with their free time is much lower (Istat, 2006, p. 116).

In this logic too, intentional works consecrated to strengthening the *leisure skills* are important for the quality of life for persons with disabilities (Fedeli, Tamburri, 2005; Schooler, 1984). In addition, to stay within the general vision, we must consider that to access recreational services, the person should be able to move with means of transportation and that recreational structures should have accessibility for disabled persons. Also working on social skills and on managing problematic behaviours should be taken into account for an intervention for a qualitative free time.

The risk for adult persons with disabilities to be confined at home or in large-scale institutions is high, running into the danger of deteriorating what was previously acquired (Chen, 1993).

In the *material well-being*, occupation and financial situation are sensitive aspects in the life of disabled persons. ISTAT statistics (2009) underline the importance of the economic situation in the life of a disabled adult. There is still much ground to cover to reach a working integration and the perception of an income suitable for good living conditions. Surely, work and participation in the communities of belonging are important aspects in growing up, here communication and interpersonal skills play a key role (Wheman *et al.*, 1988). In Italy, ISTAT statistics (2009) show rather low levels of occupation for disabled people: occupation is 11% for women in working age and 29% in disabled men in working age. Apart from quantitative investigations, research on the satisfaction of disabled persons regarding their job is also meaningful. As shown in the previous chapter, levels of satisfaction increase when the persons with disabilities are included in assisted contexts, as long as they stay “real” and competitive, and, mostly, if the persons are involved in meaningful activities (Soresi *et. al.*, 2009).

Concerning *emotional well-being*, we stress that the paradigm puts special emphasis on the satisfaction of people with disabilities and on the ability of communicating the emotions. In the situations of multiple disabilities too, it is important to see if the service staff has paid attention and assessed the subjects’ behaviour, desires and emotional state, for example facial expressions, gaze, eyes movements, posture or muscular tension, movements and other elements. Finally, this orientation could represent the logic, which should be the aim of the training of the services staff, but not only, could it also be the educational action during the lifetime and the view of a personalised life-plan. All aimed to attain, organically and longitudinally, a high level of quality of life for the persons with disabilities.

An educational intervention should not aim only self-sufficiency, to make people able to eat, dress, and wash as well as promoting the ability to choose the lifestyle preferred by the person. Apart from guaranteeing health, it is necessary to guarantee the quality of life of the person with disabilities as an inclusive dimension.

As we will see in the research that we will introduce in the next chapter, changes could come from the training of the caretaking staff of young and adult persons with disabilities who enter forms of short residency, for example, in socio-educational day centres of rehabilitation, or to forms of prolonged or definitive residence.

Adults with Autistic Spectrum and quality of life: a possible association?

We examine now the question of quality of life of persons with autism, since the autistic disorder is of the pervasive type and is characterised by compromised social interaction, verbal and non-verbal communication and an important lack of activities and interests (APA, 2013). Therefore, a disorder that includes a high risk to compromise the quality of life in all its dimensions, as is autism, has pervasive distress and strong communicative, relational and behavioural difficulties that persist in adult age (Morgan, 2008).

The intertwining of diagnostic problems and epidemiological statistics in adult age (Fombonne, 2005) signals the presence of many criticalities in the autistic adult.

In the longitudinal view of persons with autism, a precocious delay is owed to the deeply spread consideration that autism is a disorder of the evolutionary age, as it is illustrated by some diagnostic manuals too.

The family should be the first to become aware of the scarce possibility of an autonomous life for the subject with autism. The expectancy of social integration and autonomous life becomes lower, to the point that the adult person is perceived as needing less support. Therefore, low expectancies due to the pervasiveness of the disorder lead to consider acceptable even life conditions with reduced levels of quality. We must add to this the fact that adult persons with autism and their families, after the school cycle, clash with non-adequately organised services to address their specific needs. The difficulties to find an integrated network that will escort them for the lifetime and provide adequate and specialised intervention for the characteristics of the autistic subject remain relevant and evident. Therefore, as time goes by, especially for autism, the family territorial network of support loosens its grip, leaving specialist voids and intervening with prevalently assistive initiatives.

Scholars highlight remarkable differences among autistic subjects, referring not only to studying the single cases, but also to the presence of clinical situations of low functionality autism and high functionality autism, generally known as Asperger Syndrome. Despite of this distinction, some authors insist that, notwithstanding the high functionality, the level of the quality of life is below expectations and that adults with autism usually have low levels of quality of life (Howlin, 2000; Tsatsanis, 2003).

Analysing its evolution, the autistic disturb connotes itself as "almost always a lifelong disabling condition" (Volkmar, 2006). Some researchers (Barale and Ucelli di Nemi, 2003) signal a significant worsening of the general picture for at least thirty percent of autistic young persons; others, like Howlin and others (2004), stress how in the absence of a supporting network and a well-aimed skill-building action, the autistic person's syndromic picture tends to worsen remarkably.

From the few available longitudinal studies, we gather that the quality of life of adults with autism seems to be conditioned by the presence, or lack of it, of a verbal language and mental retard (Billstedt *et al.*, 2005), degrees of social competence (Beadle – Brown *et al.* 2002) or the increase of behavioural problems and forms of self-harm and aggression toward the others (Howlin *et al.*, 2004).

Studies by the University of Toronto (Brown *et al.*, 1997) show that the persons with autism who show higher levels of quality of life are those who have good speaking abilities. They have a high functionality and belong to a community; for persons with important speech impediments, when problematic behaviour is absent, access to the community and structures of free time becomes essential, using a supporting network of persons and specialised services that allow access to choice and the control of the surrounding environment (Giaconi, 2015).

Scientific literature shows the remarkable progresses at diagnostic and rehabilitative level, however, it signals a remarkable lack in setting services and organisations with specialised competent staff to assume care of persons with autism. We turn the attention to the understanding of the autistic disorder by the recent acquisitions of neurosciences. The studies highlight the strong central dysfunction, in autistic persons, of the system of the *mirror* neurons, which have a central function in interpreting the *aim* of the perceived actions (seen or heard), as well as representing their meaning and reproducing them (Williams, Altschuler, Oberman, Bernier, Nishitani, Theoret, Villalobos, Mizuno, Dahl, Kemmotsu, Müller, Dapretto, and others). In alternative, we look at another well-studied factor, which is dominant in the life of persons with autism: the lack of flexibility in thinking and behaving, a rigid and stereotyped mode of thinking, a "survival strategy" in a world that autistic subjects cannot deal with and organise. A world made of objects, events, social relations, sensorial and social stimuli that they cannot filter. Anything that represents change, from the furniture to daily activities, creates anxiety and stress. Rigidity needs order, *routine*, predictable verbal and non-verbal aspects, structured and visual learning to create what we defined as well-being. This means that learning for persons with autism, and for the young ones, remains entirely personal, it is hardly possible to generalise it, basing it on connections tightly linked to the way that single elements have been interpreted (Morgan, 2003, p. 60). It is therefore essential to guarantee an organisational proposal of the services: predictable and with low sensorial impact, where activities are calibrated according to the disorder with immediate goals of comprehension. Despite these acquisitions, scientific literature notes that there are still too many non-specialised structures receiving persons with different forms of autism without adequate organisation and preparation. At the same time and remarkably, the majority of the adults with autism do not reach a sufficient level of autonomy and need structures adapted to their characteristics.

The presence of suitable services (structures and programs) is discriminating in the life of adults with autism and their families. Their absence marks a worsening in the quality of life of persons with autism and of the *caregivers* (Mugno *et al.*, 2007).

At national level, we find meaningful experiences for professional training that go in this direction and there is the proposal to start specific structures capable to receive adults with autism (Cottini, 2010).

The training, from our pedagogical viewpoint, tries therefore to define operational modes for taking charge and for the quality of life of the persons with autism throughout their entire life, something that requires a specific competence referred to the characteristic of adults with autism and the paradigm of the quality of life.

In fact, the results coming from structured education specifically oriented toward the dimension of quality of life are noteworthy.

A program of structured intervention may include variety and possibility of choice (Olley and Reeve, 1995). It is equally possible, thanks to new technologies (apps and tablets) to increase the possibilities of communicating the choices.

These programs often see the use of agendas to structure actions and activities to be developed over time, also they can indicate or remind which actions to take and their sequence to make the movements of possible future changes predictable.

Based in the personal characteristics of the adult with autism, the agendas may use:

- Objects,
- Photos,
- Imagines,
- Symbols,
- Words.

Figurative agendas with “changes” are favoured for the self-determination, where two options are given (for example, a walk or a bicycle tour) to choose.

Therefore, it is possible to work intentionally on the levels of self-determination through the empowering the communication possibilities related to the choices, which we experienced at international level (Giaconi, Rodrigues, 2014), leading to make figurative agendas, with choice and change of activity, reaching more or less complex forms of self-monitoring.

In addition, there is an ample program of future studies toward the quality of life of persons with autism, which we can resume in the following points:

1. Implementing observation procedures to identify needs, interests and competence of adults in the autistic spectrum, especially at low functioning;
2. Experimenting procedures of evaluation of quality of life, in objective aspects as well as the subjective ones;
3. Setting supports for the full participation of persons with autism in the community life;
4. Increasing investigation on the systems of communication and interaction of persons with autism;
5. Re-thinking planning to align it with the quality of life;
6. Envisageing new devices to develop and train families and professional staff.

The pedagogical criticalities in the planning dimension

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 some significant educational experiences re-thinking routes and actions to construct life plans under the aegis of quality of life.

Many central questions have been risen by the scientific literature (Maes, Vos and Penne, 2010; Maes, Lambrechts, Hostyn and Petry, 2007; Wiersma and Zijlstra, 2007; Carnaby and Cambridge, 2002 Zijlstra et al. 2001; Felce et al., 2000), they point to the complexity of the supportive perspectives often limited from the viewpoint of service and planning structures, lack of training paths for professional staff anchored to the practices and attentive to professional changes, high *turnover* of personnel in situations of higher complexity and lack of specific training paths for the workers of the structures that receive adults with disabilities.

Apart from these criticalities, the planning dimension runs the risk of failing for lack of support in some delicate phases of transition, where the family and the subject with disabilities seem to live in an apparent “void” after the school cycle or see a supporting network that does not tighten its grip but widens it.

In fact, several phases of transition may mark the future of a person with disability, in one way or the other.

The processes and results of the transitions often influence the family in its entirety (Kraemer and Blacher, 2001; Ferguson and Ferguson, 2000; Marshak, Seignam and Prezant, 1999; Szymanski, 1994). Furthermore, the tight relation between quality of life of the family and quality of life of the single must be considered in the transitional phases (Blacher, 2000; Dennis et al., 1993), often-transitional phases hard test it[1].

In fact, the person with disabilities and his/her family find some critical issues in the various phases of the transition. Firstly, in the passage from the time spent in the school contexts to the time of insertion in various working and social contexts, should it not happen it would simply mean permanence in the family. Secondly, the passage from home, the family context, to new living realities.

At the end of the school cycle, the risk of remaining in the family context arises for the person with disabilities, with the passage of time, once considered the advanced age of the parents, the family may not be capable to provide the right supports for the quality of life (Blackorby e Wagner, 1996).

Another delicate passage presents itself; it concerns the loss of the network of the school contexts and the network of the family support, due to precarious health or death of both parents. In this case too, the transitional phase from the original home to the one of other family members (brothers or sisters) or often to other residential structures is a complex passage. Consequently, during this period, the subject with disabilities risks to have increasingly fewer opportunities of integration and participation in the community. The places frequented by the subject are home or a restricted social environment, if living in a residential centre, the subject risks to frequent people and places of the structure of reference. Many studies (McConkey *et al.*, 1981; Chen, 1993; Sturmey, 1995) highlight that disabled adults spend most of their free time at home or in large-scale institutions, during this time they are alone or with the family members, incurring into the danger of spoiling the previous acquisitions. Also in ISTAT surveys on the diffusion of satisfaction about the different aspects of daily life, persons with disabilities consider themselves highly or

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[1] The CENSIS report of 2012 shows that the presence of a person with disabilities, for example, with autistic spectrum, has a negative impact on the working life of the families, which tend to quit their jobs or ask for *part time* positions (65.9% and 68.9% in the most severe cases).

relatively satisfied of their familial relations, while the percentage of satisfaction is much lower in relation to how free time is spent (Istat, 2006, p. 116).

We must stress how the adult person with disabilities may incur in the risk, apart from the natural ageing process, of a fast deterioration of the cognitive functions due to the passage from paths of school integration and periods of intense rehabilitation to scarce contacts with the peers, a limited repertoire of recreational activities and free time, a scarce working integration and, often, a insufficient rehabilitation project.

These changes intervene significantly on the quality of life of people in general and specifically the persons with disabilities and the meaning that the person gives to the experience of life. Furthermore, persons with severe intellectual disabilities have more stressful transitional experiences partly due to limited services for adults and often not sufficiently known to the families (Kraemer and Blacher, 2001; Ferguson and Ferguson, 2000).

In fact, several authors remark that often these transitional phases lack services capable to support the families and the persons with disabilities in the decisional process toward a better quality of life.

Thinking life directions for adults with disabilities represents a path conceived and built over time and "in time" to create effectively functional living contexts oriented toward the project of life.

The person with disabilities enters, for example, residential structures because of situations that happened following the intervened absence of the family. Sometimes, this leap marks a detachment from the relational and social place of reference of the subjects. The thought of the "after us", the future of the disabled children after the death of the parents, is not supported by a training and preparatory path to be realised during the "During Us". It should prepare the person with disabilities and the family to the right and concrete possibility of an autonomous life in a structure qualified to attend the needs of their family members.

There are also criticalities inside the structures where we see situations with adult persons with disabilities housed in specific, very protected, health structures even if they do not need it; or young and adults placed in groups with older persons. Sometimes we find the opposite trend, older persons with disabilities placed in centres that receive mostly young and adults with disabilities.

The possibility of foreseeing a solution, residential or another, should not be interpreted as a solution strictly connected to depowering the family for questions linked with senility or health, it should rather signal the intentional choice of a firstly and principally “educational” “place” and “time”. In other words, contexts able to provide opportunities, relations, moments of personal realisation and acquisition of autonomous skills, as well as moments of leisure and fun.

Apart from the economic situation of the family and the reaction of the community, which are relevant questions, the failure of care taking is also due to the lack of a network to support the family, which should inform coherently and 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, to respond professionally and in a planning mode to the delicate phases of transition from adolescence to adulthood of the person with disabilities, which should be at the centre of the personal project to participate personally to the decisional process toward a better living condition.

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 shared choice of a life path makes sense in realising a meaningful project. This means that if there are the conditions to prolong the situations of life of the familial context in assisted environments, such avenue must be completed and walked with the right professionalism in non-generic or standardised situations. This takes us to the next chapter, where we will tackle the delicate question of the orientation and planning that have the characteristics of quality such as to qualify as the best life path and meaning for the person with disability and the family.

Chapter Three:

For an inclusive approach: differences, disability and Quality of Life

Di Catia Giaconi

Where to look to?

We deem important to include in our argumentation a brief reflection on the possible directions in the life of a person with disabilities.

The choice of the living solution offers remarkable pedagogical criticalities. For example, the person with disabilities obtains residence in a structure following situations caused by the loss of the family. A leap that sometimes involves parting from the place of the relations and community life of the subject. A constitutive and preparatory path to be realised during the "During Us" does not support the future of the disabled children after the death of the parents, the thought of the "After Us". It should prepare the person with disabilities and the family to the right and concrete possibility of autonomous life, even in a structure suited to the needs of the family member.

There are on record situations of adult persons with disabilities inserted in some highly protected health structures, while they do not actually need it; or young and adults inserted in a group of older persons; however, sometimes the opposite happens, that is older persons with disabilities accommodated in centres that accommodate mostly young and adults with disabilities.

Apart from the economic situation of the family and the reaction of the community, which are relevant questions, the failure of taking care is also due to the lack of a supporting network for the family, which should inform coherently and prepare on the possible specific choices for the life-plan of the family member with disabilities.

A caregiving network for the adult with disabilities and his/her family should respond professionally and in a planning mode to the delicate phases of transition from adolescence to adulthood of the person with disabilities, this problem should be at the centre of the personal project to participate personally to the decisional process toward a better living condition.

To work within the paradigm of the quality of life, we need to go toward the life path of the person with disabilities in terms of residence and of integrated networks in the community of belongings.

The life path becomes a path of meaning 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. Italian legislation supports the above, foreseeing the right of university studies with tutoring accompaniment or with scholarships, socio assisted work and pre working insertion. However, there is no supportive uniformity as well as efficient and functional educational practices for the concrete realisation of all the above in the life plan of people with disabilities.

To deepen the analysis in the next paragraphs, we will briefly scrutinise the territorial perspectives for the persons with disabilities. To avoid misunderstandings or rushed conclusions, we need to stress three aspects. Firstly, it is worth remembering that the structuring of potential perspectives finds bases on the specific needs of persons with disabilities related to the contexts of reference and life plan. Secondly, we must build bridges with the purpose of preparing to autonomous life or living in residential structures, avoiding sharp contrasts between life inside or outside the family and interpreting these services as a shared choice toward the best possible quality of life. Finally, we remind that the quality of life depends principally from services capable to connect to meaningful networks with the family and the professionalism of the persons who manage and operate in the structures. Despite the fact that significant studies shown in chapter one underline the differences in terms of quality of life between subjects living in the family and those in institutionalised structures (Silverstein *et al.*, 1988), between persons living in small structures and the ones living in large scale ones (Lifshitz, Merrick, 2003).

In the supportive network for the families and for persons with disabilities, residential structures can offer short and long term services.

Centres for short-term stays are planned and organised to receive persons with disabilities for short stays (few days or some months) for reasons that may vary from a parent or family member's sickness or to provide a "relief" to the family. These situations are the norm also in the experiences of families with adult persons with autism, considering the total absorption caused by daily cares. Thanks to the short stays, the family has time to recover and turn the attention to other activities of interest. The most promising perspective regarding short-term residence concerns the possibility to use them to experiment life away from the family within the frame of an ample life project, to make wider space for activities turned to a precise qualifying project and preparatory *steps* for the insertion in structures for prolonged permanence. The realisation requires attentive and long planning harmonised with the family and the community of belonging, as well as with daytime centres and centres for prolonged stays.

Residences for prolonged stays represent living solutions, they are provided in homes and apartments, which accommodate a limited number of persons. At structural and ideological level, these structures contrast the logics and philosophy of large institutions where attention goes to assistance rather than the taking care of the person (Giaconi, 2012). The services organise themselves on the twenty-four hours and articulate in a series of interventions aimed to the project of life. In our territory we find a wide range of residential services in accordance with the specific regional laws (Nursing Homes, Housing Communities, Apartment Groups, Services for Autonomy, among others), with functional parameters that may differ according to the autonomy of the guests and their needs of education and assistance.

For example, housing communities for disabled persons are residential structures destined to adult subjects conditioned by disabilities who are often bereft of proper familial reference, but have a good autonomy, which does not require the continuous presence of caregivers (L.R. 20 of 6/11/02 art. 5 comma 1).

A socio-educational-rehabilitative community is a residential structure with a community character that caters for adult persons conditioned by disabilities, who have no or limited autonomy and do not require continuous medical assistance, who are temporarily or permanently deprived of family supports or whose permanence in the family has been evaluated impossible or contrasting with their life plans (L.R. 20 of 6/11/02 art. 5 comma 2).

A protected residence is a residential structure destined to persons conditioned by disabilities with severe psychophysical *deficits*, who require a high degree of assistance with interventions of the educative, assistance and rehabilitative types, with a high level of socio-medical integration (L.R. 20 of 6/11/02 art. 5 comma 3).

“Apartment groups” characterise as a service functioning for the satisfaction of the needs of the person, maintaining the skills and acquired levels of autonomy and the path of personal development and social insertion. A special concern should go to the pre-existing network and to the structuring of networks to support the single and the group of guests. In such a view, promotion activities and integration with groups of volunteers have been encouraged. In certain circumstances, the received persons can frequent a daytime centre or participate in working activities.

We move now to a description of the perspectives of the daytime centres for persons with disabilities, set for the disabled youth after school.

The daytime centre for persons with disabilities is a territorial service, which provides interventions of educational, rehabilitative and assistive character.

It is a non-residential structure open for at least eight hours a day, for six days a week, with therapeutic-rehabilitative functions tending to prevent and/or stop the processes of relational isolation and marginalisation, as well as preventing and reduce admission to institutions.

The centre operates rehabilitation paths aimed to attaining the autonomy of the users and to re-socialisation through employment programs, to learn specific competences to use for employment and programs of social animation

Support meetings are organised with the families in connection with the territory, beside the activities in the structure.

The socio-educational-rehabilitative daytime centre is a territorial structure active during the day attending subjects conditioned by disabilities with important impairments of the functional autonomies, the subjects have completed the compulsory school cycle for them there is no expectation of working or training insertion in the short term (L.R. 20 del 6/11/02 art. 5 comma 4).

At the base of these structures is the necessity to provide programs of enablement to promote those skills that we defined “living skills”, trying to avoid that young and adults with disabilities stay with the family for the duration of the day, suffering disadvantages from the social viewpoint. Ultimately, they would not frequent their peers to the detriment of cognitive development. Daytime centres should manage the training of groups and avoid that young people mix with older ones and vice-versa, running the risk of presenting generalised and useless activities for the quality of life. The centres effectively offer the best opportunities to develop the abilities promoted by the dimensions of the quality of life: autonomous skills, which allow the person to become self-sufficient and live in line with the social contexts of reference, to the ability of manageing free time (Cottini, 2007), as well as the promotion of forms of self-determination in daily life and in the life plan. Furthermore, these centres should prepare the persons received to real and inevitable changes such as the loss of a parent (Morgan, 1996) or a change of home. We can face these transitional moments prepared, so that they would not result difficult to deal with and, especially, confined to a mere assistive administration. The structures themselves can organise programs of *parent training* to support the family during the transitional phases of the disabled family member.

In this picture, the structures that promote the contact with nature are of remarkable interest to guarantee new ways for the quality of life and for the integration of adults with disabilities, they are also known as *farm communities.*

A *farm community* is an agricultural-residential community where persons with disabilities live in a protected and natural environment. Many such experiences started in the Sixties, for example, for adults with autism. These places started with the aim of providing spaces for adult life, characterised by natural *settings* and working experiences, meaningful recreational and social activities with attention to enablement programs.

Farm community vary for dimensions, intervention strategies, educational models, family involvement, verification instruments, background philosophies and cultures; all of them have some elements in common, which are considered essential for taking care and quality of life for people with disabilities.

The rural living context is fundamental, it has small scale, it permits meaningful experiences and a wide range of enablement activities based or aimed to do real agricultural jobs (horticulture, agriculture, processing the produce, breeding, and more) placed within a precise temporal dimension. The changes are predictable since they are favoured by the natural cycle of days and seasons. Work and efforts in meaningful activities represent the focus of a quality intervention. Furthermore, the work has no serial, repetitive, mechanical and de-contextualised character.

Any person with disabilities and level of complexity deals with real work as part of a project and of a collective life. The residents are constantly involved in jobs and activities that can provide direct meanings, use and results.

Life in *farm communities* has a constant opening and connection with the territory, through a system of trading linked with agriculture and breeding (buying and selling of produce, materials, dealing with foremen and more), amusement and social events (feasts, fairs, shows and more.), sport activities and organised relaxation. Families are involved with the persons with disabilities, as well as citizens and the community.

The experiences highlight a better quality of life perceived both at subjective and objective levels.

A further interesting perspective for the quality of life and the inclusion of the persons with disabilities is offered by the research of adequate and sustainable forms to allow disabled persons and older persons, to live at home providing safety, support in daily life activities and promoting autonomy and active participation (Casazza *et al.*, 2002).

Ambient Assisted Living is a program started by the European Commission (2007), oriented to the quality of life of older persons and weaker population through the support of information and communication technologies (*Information and Communication Technology* - ICT). It is based on an inter-disciplinary approach; experimented *software* and *hardware* solutions, they are devoted both to environmental and personal levels to improve the quality of the life of older persons or persons with disabilities.

For example, we can think to the micro-systems worn to apply *Ambient Assisted Living* oriented to the mobility and disguised in the clothing (belt, watch, shoes), capable of measuring the dynamics of human movement and performing the monitoring of physical activities, and events like falls, postures, perambulation. In other words, a network of sensors records any movement of the day, eventual falls, or physiological anomalies of the person, or possible changes and emergencies within the living context. There are also many audio-video sensors or generic environmental sensors, which provide information, related to the persons' daily activities, their behavioural conduct, including the detection of eventual indicators of alarm for the family members and staff. The wearable sensors are used also to value the index of the quality of the activities performed, including sleep and movement among others. Environmental sensors are installed to detect gas, electricity, opening and closing of doors and windows.

The frontiers of research push toward the creation of virtual communities of reciprocal help (Rashidi, Mihailidis, 2013, p. 580) or caregivers who can monitor remotely and intervene when needed.

Generally speaking, the complex articulation of the system of *Ambient Assisted Living* is turned toward *activity recognition* and behavioural analysis, with special reference to stainless sensors or video devices to detect physiological parameters and environmental sensors, for the safety, perambulation and mobility in the surrounding environment, access and use of structures such as sofas and beds. Finally, comes the manageing of first aid requests, memorising multiple data for a synchronic and diachronic analysis, elaboration and analysis of the information coming from sensors for general detection, at quantitative and qualitative level of activities and behaviours.

We can say that the scopes of *Ambient Assisted Living* enter the framework of quality of life. Consequently, the finalities aim to prolong the stay in the living context of the person with disabilities or in old age, increasing the possibilities of self-sufficiency, safety, mobility, autonomy and interaction with the context and the network of significant figures. A dimension perfectly aligned with the new European prospect of *Horizon* 2020.

The national programs of research are noteworthy; they support projects to develop innovative solutions aimed to improve of the quality of life of persons with disabilities and older persons. Such programs pretend reducing the possible overall costs of home assistance or similar situations, anyway out of the domestic walls, considering the statistics of the "ageing" Italian population.

The path that we desire does not see only the possibility to implement remote devices to control the physiologic parameters and behaviour. On the contrary, we propose to favour strengthening procedures and devices that allow quality life to disabled persons in their environment, which is made of spatial dimensions, but also of relationships. We, therefore, wish the promotion of the quality of life within an inclusive view.

We consider the perspective of special pedagogy essential within the inter-disciplinary relations as the frame that means planning supports turned to the promotion of the quality of life of persons with disabilities, while respecting a personalised planning. In fact, we must consider what quality of life means for the person with disabilities, what it means in a particular period of life and in future perspectives. The need is indeed to set devices capable to accompany the changes of a person who is growing and think integrated forms of mediation between the person and his/her life plan, programming systems that allow a deep integration with the contexts of life within the scope of inclusion.

How do we plan a meaningful dimension?

We believe that for persons with disabilities the trajectories of life must be meaningful. This cannot be attained if the network of services stops supporting the family and the person with disabilities during the delicate phases of transition. Sharing the choice of a life path makes sense in realising a meaningful project.

This means that conditions to prolong situations of living in the familial context in assistive environments provided, such path must be contemplated and explored with the right professional attitude in non-generic and standardised situations, but personalised ones instead.

The same must happen for residential structures. We have already advised the necessity to create services to prepare to residency, however, we would like to stress that some indicators could characterise quality living in the structures for persons with disabilities.

The possibility of owning music CDs, computers, radios and be able to buy beverages during temporary going-outs are examples of the desires and expectations referable to the domain of material well-being. The possibility to choose elements that concern the disabled person is one action going toward self-determination. Other elements of quality in the project of life are setting reserved spaces, a personal room where to keep objects and souvenirs and have personal space, having the possibility to take personal decisions, such as establishing the time to go to bed, choose a place to visit, look after a pet. Doing meaningful jobs, foreseeing activities to empower autonomy and social interaction, foreseeing activities and roles in the community, allowing the chance to choose are equally important factors.

The trajectories of meaning can be operationally defined by a life plan in the sign of the paradigm of the quality of life. Is it possible to construct objectives aligned and coherent with the indicators? Following this thread, we can formulate some questions as guidelines based on the scheme offered by several scholars (Adams *et al.*, 2006; Sand, Doll, 2005).

Among the indicators of a program of quality, we must stress the following: relevance, observability, functionality, temporality, monitoring, realism, regulation and participation.

The goals of the programs to improve the quality of life should answer the demands that will follow.

Are the rehabilitation goals relevant and significant for an individual life plan?

Can they be translated in observable behaviour? The goals must translate into observable behaviour, through a clear operational language, which should not leave room for uncertain terminology.

Are they suitable for the subject and his/her health conditions? This means that the activities must be suited to the chronological age of the persons, rather than the mental one, because a job focused only on the mental age would signify a fall in expectations and levels of performance.

Are they functional to the daily needs and significant in relation to their contexts? The goals must be functional to the daily needs. Persons with disabilities must be actively involved in meaningful activities within the contexts where persons belong and refer to; activities that allow persons to assume specific roles.

Are the goals temporally weighted and limited in time to verify their attainments?

Are improvements and eventual deteriorations traceable? This becomes essential in order to re-plan the project of life, which characterises itself for the flexibility.

Are they classifiable and quantifiable? A program of intervention must have indicators at qualitative and quantitative level, as to appreciate the efficiency and efficacy of the intervention.

Are they obtainable in terms of human and material resources? In other words, the goals must be realistic, or to be obtainable with the available resources, to avoid dangerous failures which would affect the self-esteem of the person with disabilities.

Are they functional to increase autonomy, self-determination, and personal *empowerment*? Are they aligned to the person's desires? We would say today that goals must aim inclusion, must make persons more able to make choices based on their needs and desires.

Do they favour social participation and relations with friends, family and context? The program must place itself inside an ample project of participation to the community life.

In this way, the service directs its interventions toward quality, widening the qualitative offer of the service and of the persons admitted.

What changes in taking charge of the person with disabilities?

Over time, the taking charge of the adult includes a reflection that concerns ageing. From the specialist diagnoses based on specialist tests, the pedagogical perspective expresses itself directly in planning educational interventions finalised to the promotion of the quality of life for persons with disabilities and their families.

In the texture of the domains of quality of life, we find the need to carry out pedagogical reflections to train specialised staff and for the analysis of the quality indicators in organising a service and the programs.

The conceptual structure is not an abstract and useless theory, this element allows attainment of the most suitable practical goal, and the making of a repertoire that can rely on a variety of elements according to the necessity with instruments chosen with no regards to fashion.

We want to stress the possibility to align the life plan of a person with disabilities with the paradigm of the quality of life, considering that general reflections concretise in reference to the person and the interactions with his/her own contexts, in an ecological and longitudinal view.

We believe that in this phase we should mention briefly a great change in approaching the complexity of the person with disabilities. The ecological perspective of quality of life has surely promoted the development of new reflections but not always, as we will see, in researching awareness about the new educational practices. The centrality of the person connected to the network of relations and the physical context, as well as the social and cultural contexts of the community of belonging, should be maintained. Therefore, the person cannot be confined to a mere evaluation of the *deficit*; in the medical perspective, the intervention on the quality of life is not seen as a recovery and therefore as the absence of the disease. Disability seen in the dynamic of the person on the surrounding context is the expression of the limits of the individual functioning inside the contexts of belonging. Such vision widens thanks to meaningful contributions like the *International Classification of Functioning* of the World Health Organization (WHO) and the model of functioning and support to intellectual disability suggested by the *American Association on Intellectual and Developmental Disabilities* (AAMR, 2002). The paradigm of quality of life integrates these perspectives with the perspective of the domains.

In this view, multi-disciplinary evaluation goes toward the recognition of the person in terms of intellectual skills, adaptive behaviour, participation, interaction and the social and medical roles of the context. At the same time, the evaluation will consider the needs of the subject and the areas of intervention, therefore, the necessary supports for the quality of life of persons with disabilities. All of this is needed to set programs aimed to invest resources and set supports for the improvement of the individual condition of the person and the quality of life.

Is targeting educational and rehabilitative programs based on the mere individual functioning well enough? Individual functioning that is expected and promoted after the interventions corresponds to a level of adaptation to the structure's context; however, it loses the inclusive perspective. Nevertheless, the planning must start from the need of support, which goes from the dimensions of the quality of life in the case in which persons with disabilities perceive personally, or verify objectively, that they cannot attain good levels of quality of life. Unsatisfactory domains of quality of life show the needs of the persons, the need of support is the subjective and objective perception of the lack of specific spaces in our daily life. Therefore, we draw a qualitative and quantitative profile of the needs of the disabled person. Such needs of support, which correspond to the domains where the person does not attain a good quality of life, help finding the priorities and the mapping of the resources and supports to be provided for the purpose of a better quality of life of the subject. Therefore, the focus becomes the measurement of the dyscrasia between the functional condition of the person and the typical levels of quality of life within the social context, as well as in practical and referential terms. The discrepancy existing between skills and requests coming form the surrounding context could be evaluated in terms of support areas in the development of the person or in teaching and educational contexts, home living, community living, work, health and safety, behaviour, socialisation and legal protection. In other words, the distance between the functioning of a person and the quality of his/her life in the community, and not the service or centre where he/she lives. This discrepancy lets the supports to improve the quality of life of people with disabilities emerge, that is, real needs are found inside the history of the subjects and the contexts of reference, the support needed by the persons is assessed to obtain the best possible level of functioning, to increase the level of independence in life and improve its quality.

The supports are resources and strategies poised to promote development, instruction, interests and the personal well-being of the subject, while improving the personal functioning.

The services represent a mode of support provided by professional operators (Luckasson, Schalock et al., 2002). Therefore, the supports have different functions (teaching, assistance at work and at home, Access and use of the community services, among others); they work to reduce the discrepancy existing between the functioning and the expectations of a person and the demands of the surrounding environment. We can find some experimentations going in this direction in several ANFASS committees at national level (Anfass, 2007). In the perspective of an operative application of the essence of the quality of life and of the principles that we have discussed, we will focus on the Supports Intensity Scale (SIS) used since 2004 at international level and in Italy since 2007, thank to the adaptation made by Cottini et al.

The relation of the functions of quality of life and educational interventions is its most conspicuous aspect. Similarly, the guiding principle is the quality of life of persons within the community of belonging.

To apply the construction of the quality of life we would like to remind some aspects related to the domains and indicators. The domains are constituted by all the factors that make the well-being of the person, they represent the essence of the quality of life; they include emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion and rights. The indicators are perceptions, behaviour and specific conditions for the domains of quality of life that reveal the well-being of the persons, in real or perceived terms. The criteria for selecting the indicators must be (Schalock, 2006): validity (for measuring what we need to measure), reliability (agreement between subjects and assessors), sensitivity (it observes the changes), specificity (it reflects the situations), sustainability (realistic economic terms and human resources in a wide temporal perspective), timing (referred to the person), longitudinally verification (coherent indicators), cultural sensitivity (it reflects the culture of belonging).

In other words, the indicator translates the domain in terms of subjective quality and contextualises it. In this view, the indicator defines the units of measurement of the personal functioning or the context and of what is necessary to assess how to reach the planned goal, reporting the results of the intervention. Therefore, the intervention can be assessed in relation to the improvement of the quality of life with an instrument that is objective, as it qualifies and quantifies the results. It enables appreciation of the benefit produced by the intervention, using a tool that is considered reliable. Consequently, it allows the comparison between starting point and situation created by the support that was supplied.

What changes in the planning?

Scientific literature on didactic planning focuses on the concept of alignment (Biggs, 2003; Laurillard, 2012). We believe that this concept is central in educational planning and in life plans of persons with disabilities, a strategic mode to attain the implementation of the quality of life. Various procedural phases characterise the construction and promotion of a life plan at school or in a daytime service or residence: assessment or initial evaluation, ecological balance[1], planning the supports[2], supply of supports and the development of the supporting activities, in-progress monitoring and assessment of the results.

In this view, multi-discipline turns toward knowing the person from the viewpoint of intellectual abilities, adaptive behaviour, participation, interaction and social, medical and contextual roles. At the same time, it considers the needs of the subject and the areas of intervention, or the necessary supports for the quality of life of the persons with disabilities. All this is to plan a targeted program, use resources and set supports for the improvement of the individual conditions of the person and the quality of life.

In an educational project, many dimensions must get in line to guarantee the alignment, which is the duty of professional workers in the structures that receive adults with disabilities.

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[1] The ecological balance consists in a scheme of analysis of the operational individual conditions of that is used in monitoring the results while orienting the needs of understanding and supports for the domains of life.

[2] The supports are resources and strategies that improve the relevant results for the person with disabilities (Schalock et al., 2002).

The following types of alignment are recognised:

- The goals of the structure and the project with the goals of the persons with disabilities;
- The functionality and needs of the person with the domains of the quality of life;
- Resources and strategies; therefore, the supports that improve the relevant results for the persons with disabilities;
- Educational activities and strategies;
- Assessment forms.

Such a structured life plan represents an instrument strongly projected toward the quality of life and accompany the persons with disabilities and the changes, over time, in their lives in relation to the needs, in their contexts. The goal targeted is providing the best possible life.

Interesting fields of research and action originate from there to re-think life plans in their concrete realisation and implementation. The projects should not be mere projects on paper; they should enable actions and activities for the quality of life of persons with disabilities.

The first form of alignment concerns the goals. The project's goals and the different levels of intervention (clinic, rehabilitative, educational and social) must focus to promote the improvements in the quality of life and facilitate the conditions of a life adapted to the context (Cottini, 2008, p. 35).

The goals must be chosen among competences oriented toward adult autonomies and competences in self-determination, "life skills", maintenance of a good support network, an aware management of personal health, free time, occupation, identity and self-planning.

The goals must be relevant and meaningful in the life plans of persons with disabilities; they must operate based on the needs of daily life and in real contexts to facilitate social participation in family, friendship and community networks. Furthermore, they should widen the levels of self-determination[1]. Wehmeyer (2010)

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[1] In this aspect, international research promoted assessment procedures for self-determination for persons with disabilities, and as instruments for self-assessment and hetero-assessment. For example, we report the scales of evaluation of self-determination by Soresi and Nota (2007). The scale of evaluation examines self-determination in the activities of daily life. For example, if the person with disabilities can spend money or express emotions or, also, can freely participate to activities during the day, and, in general, be able to make personal choices.

showed that self-determination does not depend from the surrounding contexts (*must*) and the operational conditions. International research (Lachapelle, Wehmeyer *et al.*, 2005) showed that self-determination is a crucial dimension to improve quality of life and social inclusion. A high level of self-determination increases people's possibility to have a positive adult life, for example, in work, autonomy and independence[1].

The second form of alignment concerns the alignment between the functioning and needs of the person, recorded by the multi-disciplinary *assessment*, with the domains of quality of life (Schalock, 2007).

The *focus* therefore measures the dyscrasia between the person's functioning condition and the typical levels of quality of life in the social, cultural and practical context of reference. Therefore, the assessment concerns the distance between the person's functions and the quality of life in the community of belonging, not only in the services or in residences in use.

This discrepancy shows the emergence of the supports to improve the quality of life of persons with disabilities. The effective needs lie inside the subject's history and in the contexts of reference. The supports needed by the persons to attain the best possible operational level are assessed to increase the level of independence of our lives and increase its quality. What has been described previously concerns the third form of alignment: its resources and strategies, which are the supports that improve the relevant outcomes for the persons with disabilities (Schalock et al., 2002).

Consequently, the planning must start from the needs of support, which is the measure of the quality of life when the person with disabilities perceives subjectively, or ascertains objectively, that he/she does not get satisfactory levels of quality of life. Non-satisfactory domains of quality of life show the needs of the persons, the need of support is undoubtedly the subjective and objective perception of the lack of quality in specific areas of our daily lives. Such needs of support correspond to areas in which the person cannot obtain a good quality of life, they help finding the priorities and map the resources and supports to provide in the perspective of improving the subject's quality of life.

The discrepancy between skills and requests could be evaluated in terms of areas of support in developing the person or in learning and educational contexts, at home

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[1] Therefore, the life's level of satisfaction is tightly connected to the level of self-determination (Wehmeyer, 2009). This example is even clearer for persons with disabilities.

and in community life, on the workplaces, in health and safety contexts, behaviour, and socialisation and in legal protection.[1]

The correlation between operation, quality of life and educational interventions is the most relevant aspect, and the guiding principle is the quality of life of the persons in their communities.

In fact, the perspective does not put aside the necessary action of *assessment* with subjective and objective instruments; on the contrary, it values it to align it with all that the person regards as important in life. This presupposes the involvement of the person and the family to value the desires and expectations of the adult person with disabilities; for the expectations of family and community of belonging to observe the discrepancies in skills, desires, expectations, goals and performance demanded by the contexts of reference.

This leads to the re-thinking of the life plan: to integrate these visions and produce aligning actions deriving from the different areas of possible, viable and functional supports to improve the quality of live.

Spaces too should align to the domains of the quality of life.

Defining operationally this perspective means, for instance, having a personal space of *privacy*. In observing the various organisations of the structures attending persons with disabilities, it is important to understand if the services provided respect the *privacy* of the admitted persons, if the structure has private rooms, which may be personalised with objects and pictures that can provide a sense of history, present and future of the person with disabilities.

It is important to favour “adult” working modes within the life project.

Occasions of personal enrichment and learning decrease with the time for persons with disabilities; in general, the educational activities proposed are repetitive, scarcely meaningful or coherent with the age of the subject. On the contrary, regardless of the mental age of the subject, planned activities should be pertinent with an adult life plan, not like an “eternal child”.

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[1] There was evidence of several experiments in this field by the scientific committees of ANFASS in Italy (Anfass, 2007). We will talk about the *Supports Intensity Scale* (SIS) used at international level since 2004 and in Italy since 2007, thanks to the adaptation by Cottini *et al.*, in the perspective of operational implementation of the construction of quality of life and the principles that we have been describing.

As highlighted in the previous chapter, the levels of satisfaction increase when disabled persons enter assisted, but at the same time "real" and competitive contexts, especially if they are involved in meaningful activities (Soresi *et. al.*, 2009).

Activities to be encouraged are therefore meaningful activities in real contexts, tutorials and simulations of real problems.

International literature (Irvin, Close, Wells, 1987) has long been aware that the possibility to improve the quality of life of persons with disabilities is closely linked to the availability of services and *training* to or for:

- Contain the impairment of the cognitive requirements (Cottini, 2008, p.36);
- *Daily living skills*, functional skill in daily life (domestic skills and care of the living spaces);
- *Community living skills*, as skills for living in the community (mobility within the community, access to services and money, social skills and more), which are regarded as the most functional skills for social integration (Ianes, 1984);
- *Leisure skills* (Fedeli, Tamburri, 2005; Schooler, 1984)[1];
- Capacity of self-determination[2].

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[1] We must keep in mind that access to recreational services we need, as to keep the overall picture together, that the person should be able to move on means of transportation and that the recreational structures are accessible to persons with disabilities. The work should deliberately focus on social skills and management of problematic behaviour, for an intervention on the free time.

[2] For "self-determination", we mean "primary causal agent in one's life and to make choices regarding one's actions free from external influence or interference" (Wehmeyer 1996, 2002, 2009; Wehmeyer, Schalock, 2001). Self-determination is not linked to the ability of persons to act in total autonomy this aspect would be missing in persons with severe disabilities; however, it is tightly linked to participation to the decisional process (Wehmeyer, 2009). In this view too, adult persons with disabilities find themselves in living contexts where the others (family members and operators) frequently choose in their place how to organise their time or what to do or not to do with it. Wehmeyer e Schalock (2000) describe four essential characteristics of self-determined behaviour: autonomy, self-regulated behaviour, psychological *empowerment* and self-realisation (Wehmeyer, Schalock, 2001). Autonomy relates to the capacity of action of the person with disabilities in relation to the system of personal preferences and interests. Therefore, the capacity to take decisions and make choices. Following this direction, it is important to observe if there are family members and operators surrounding the person with disabilities, who, beside paying full attention the person's interests and preferences, allow the person to act starting on his/her personal preferences and therefore create spaces and opportunities for independent action. Similarly, it becomes crucial to consider if disabled persons, even if accommodated in residential structures, have the choice of

The best results in terms of quality of life occur when persons with disabilities are actively involved in meaningful activities in their context of reference, the activities should enable both active participation to community life and assumption of specific roles.

Several authors (Cannella et al., 2005; Sanderson, 2002; Green et al., 2000) stress the need to empower the procedures to learn the needs of people with disabilities within the domains of the quality of life and facilitate intervention strategies capable of implementing life conditions. These tools allow the enhancement of eventual structural characteristics and procedures for the presence of objective aspects (dietary and medical conditions and more), as well as other subjective aspects of the quality of life (enhancement of satisfaction and expectation among others). We presented an overview of these instruments in chapter two; they allow also a triangulation of the methodologies (*self-report* and *report*).

Which training for the professionals?

We believe that, for what we are concerned, the training of trainers and pedagogues must keep in account these perspective actions too, in terms of quality of life for persons with disabilities. During their schooling years, students should not only listen about children with disabilities but also about adults with disabilities and ageing adults with disabilities. Interdisciplinary teams should already move in this direction to confront with such scenarios and situations.[1]

Furthermore, the problematic calls for the training of the personnel working in the services. The training should start from monitoring the attitudes toward the quality of

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two options in their daily programs, for example, in terms of activities for the free time. Self-regulated behaviour includes the ability of interpersonal *problem solving* and the perception of personal control. Here too, putting into action educational procedures to promote the capacity of *problem solving* in familial or caregiving contexts. It is also necessary to watch that the person has the opportunity to make experiences in terms of control and choice; or, if effective practices of intervention on the definition and attainment of real goals. Psychological *empowerment* concerns the work on the levels of self-sufficiency and an internal *locus of control*, while self-realisation relates to the degree of self-awareness.

[1] We stress the “Guidelines for services of quality for the definition of the Standards of Quality in services for disabilities in Italy” (AIRM, 2010), on which many structures are converging and specialising.

life of disabled persons to produce new devices for the training and to make professional changes.

Some important conceptual points emerge from the threads of French research in this field, they avoid the mere parcelling of the tasks of the expert professional operators, as much as exploring the nature, modes of construction, articulation and training, in initial training and lifelong learning (Altet, Charlier, Paquay, Perrenoud 2006, 19).

This consideration enters a scenario characterised by strong and fast social, economic and technological changes; as well as by quick and deep changes that involve educational systems and professional profiles. All of this joins the peculiarity of the contexts of educative communities. The structures accommodate adults with disabilities with very specific characteristics, who, as scientific literature points out, demand planning services and the training of personnel who should know the peculiar learning styles and profiles of persons with disabilities and autism. In such a way, professionals could answer, with their educational practices and actions, the special educational needs and the quality of life of the persons admitted by the services, going beyond the assistance-based model (Giaconi, 2012) and the minimum requirements of the law (Morgan, 2003).

In this view, the professional operator as such is recognised as the one who possesses specific practices and professional competences (Altet, Charlier, Paquay, Perrenoud 2006). This becomes the context where to ponder a new approach to initial and continuous training, which lets the necessity of a new synergy between theory and practice appear.

This perspective, found in the variety of the interpretational models (Idem; Donnay, Charlier, 1990), allows appreciating the vision of a professional with a set of competences lying surely with specific and multiple professional knowledge (for instance, they consider the knowledge related to procedures and tools to judge and intervene in a specific context of disability). However, it becomes essential to understand also the "schemes of action (…) used in practicing the profession" (Altet, Charlier, Paquay, Perrenoud 2006, 18). The latter are intended as *habitus* (Ibidem. p. 20) that belongs to a professional and determines his/her perceptions, interpretations, analyses and decisions. The *habitus* allows the professional to cope with the issues found in complex situations. In fact, Perrenoud (1994) stresses that practice is *"(…) expression de l'habitus (…) ensemble des schèmes de perception, de pensée, d'action* *et d'évaluation qui nous guident à chaque pas dans l'illusion de la spontanéité"* (Perrenoud, 1994).

In regards to professional development, the work by some researchers (Freeman; Richardson) suggests to make the beliefs of professional operators available and heard, to allow their examination and eventually modify them with changes in practicing.

Next to these reflections, we recall the proposition by Schön (1983) focused on the thinking and the reflections of the operator which are rooted in the action, minding to explain what means building professional competences "based on experience" (Altet, Charlier, Paquay, Perrenoud 2006, p. 21).

Remarkable interest comes from the questions raised and poised by some researchers who tried to investigate how to involve and facilitate training that conjugates theoretical and practical knowledge. To find how to empower the participation to the development of knowledge related to professional competence and make participation to research a modality to favour the professionalization and reflection on the action (Ibidem. p. 22, Magnoler, 2008).

In other words, new devices for training must be activated; they should establish close links between courses and internships, providing an adequate supervision of the practice, which should enable experimentation and analysis (Darling-Hammond & Baratz -Snowden, 2005). The significance of structured paths for the analysis of educational practices is high, as shown by the current scientific research (Vinatier, Altet, 2008). The same applies to the awareness and the transformation of the schemes of action or of the *habitus* (Perrenoud, 2006), using various training devices like reflexive practice; exchange of representations and practices; mutual observation; clinical writing, life story; video learning and more.

In short, this vision becomes important in initial and continuous training, where devices going toward awareness must be activated, for a theoretical and practical re-thinking where unspoken knowledge could be spelt out (Nonaka, Takeuchi, 1997).

Chapter four

Finding post school perspectives: training and work for inclusion

Di Maria Beatriz Rodrigues

Introduction

Which relation should exist among State, labour and diversity? Should differently able subjects be segregated since the school desks, as it happens in Brazil, or should they be included in the productive life as it happens in other countries? Many concepts originate from this discussion; they include acceptation, discrimination, inclusion, normalisation, and hierarchy of differences, among many others. One certainty remains, it is not easy to deal daily with disability, numerous examples confirm this assumption. Because discriminations against women or black people exist alongside others, that are apparently less frequent, like discriminations against differently abled people, and people with physical or mental disabilities.

The diversity that we meet here relates to different abilities. In this chapter, we propose a discussion on social inclusion from the productive point of view, or, how differently able people are or could be integrated into work contexts. In Italy, the law that closed the mental hospitals in 1978 regulates inclusion, and in 1992 it allowed children with disabilities frequenting regular classes, this will provide an epistemological reference when treating the Brazilian examples. We include in this discussion an entrepreneurial example of inclusion of people with disabilities working in a company. Our intention is not to compare the success in implementing inclusion but to propose examples to discuss the themes of inclusion at work and how to bridge the gap existing between the end of schooling and the beginning of the working life.

The following questions are at the basis this text. Can companies actively participate to include people with disabilities with the help of governmental public policies? What is the role of the companies? How should school prepare the young disabled to enter the job market? The backdrop of this discussion is a pressing need, an *anaghi*, linked with the construction or solidification of a Brazilian *welfare state*.

The chapter will be divided into six sections. Firstly, we start from the concept of social wellbeing, or *welfare state*, and a short history of its development in Europe to discuss the present moment and the notion of *welfare mix*. Secondly, we discuss examples of public policies of social protection for diversity in various countries. Thirdly, we reflect on the epistemological foundations of the models of inclusion in the two different countries. Section four approaches the importance and the complexity of working with people with disabilities. Section five presents examples from Italy and Brazil on schooling and labour inclusion. Finally, we contribute with an analysis of work as instrument of emancipation, and we discuss the responsibilities of companies and the possible contributions that these can provide, as well as the benefits to be gained with the participation in public policies in introducing differently able people on the workplace.

1. Social Background for inclusion

To obtain an overall legislative and historical framework, it is important to see how social inclusion was conceived in a project of social equity in each of the countries. Following our framework about the quality of life of disabled adults is one of the indicators to analyse the crucial transition from school to work.

The welfare state is the system that guarantees satisfactory living conditions to a population as projected and practiced 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 to provide dignified life. These systems work through taxation and redistribution of income, that is, a percentage of Gross Domestic Product (GDP) goes to guarantee and maintain the living conditions of the population.

The idea of *welfare state* goes back to the end of the nineteen-century. However, the first effective actions took place after the World War I, during the Great Depression in the Unites State, where the famous *New Deal* was conceived to tackle unemployment and progressive impoverishment. Sennett (2004), in his research on the origins of the *welfare state* in Europe and United States, affirms that, in 1929, the crisis hit workers in different ways, revealing a precarious working class highly susceptible to economic changes.

The golden age of the *welfare* state was between 1945 and 1975, in a period of post-war economic expansion when the benefits offered to the population increased.

Already in the mid-seventies, this reality began to change. However, the end of the prosperous period happened in the eighties with policies of economic austerity and cost cutting in several countries, as it happened with the governments of Margaret Thatcher in the United Kingdom and Ronald Reagan in the USA. With these transformations, the centre of the debate about the future of social protection systems was split into positions that showed two possibilities: one of dismantling it and another of resistance to maintain it.

The typology of Esping-Andersen (1990) introduces the notion of *welfare* regime, how the interdependencies among public institutions, market and society, produce a protective system in a given reality. According to the author, the models vary, when elaborating their *welfare* states, every country followed different concepts of what, according to them, meant “good society”. The common goal of these countries, in the primordial phases of elaboration, was to solve the post-war social inequalities, but the trajectory of each society depended on the founding characteristics and their priorities in terms of social justice. According to this typology, the solutions based on individualism are preferred in the Anglo-Saxon countries; the solutions based on social equality and universalism are typical of the Scandinavian countries, while solutions based on corporatism and concessions of subsidies are found in countries such as France, Italy and Spain.

At the present moment, by reasons such as limited economic growth, increased taxation and the ageing population in the Western countries, the debate between dismantling and resistance of the welfare state seems partially overcome. Nowadays, the focus lies on the capability of re-structuring of each country and the possibilities to find alternatives for the systems of social protection. Consequently, the arrival new political actors and the partnership between public and private are themes that gain in relevance. We discuss the passage from the classic *welfare state* to a system of *welfare mix*, since the State, finding difficulties to answer increasing difficulties, looks for aid in the private sector (Powell, Barrientos, 2004; Hogg, Baines, 2011; Longo, Notarnicola, Tasselli, 2015). We could mention the social cooperatives of Italy that, in partnership with the State, assume an important role in social assistance of children, older people, people with disabilities, beside services linked with hygiene, environment, housing, among others. Also, one of the largest supermarket chains in Italy is a social cooperative and, in this case, the supply of services is clearly linked with profit.

The present re-structuring of the *welfare* in Europe is incremental and objective, it prioritises cost control, re-commoditisation and modernisation of the systems. A big difference between the original post-war *welfares* and the present ones is precisely their commoditisation. What was considered a duty of the State in the past, today is being re-thought with attention to reducing the benefits and the restriction of the alternatives of participation in the social security system (Agostini, 2005). Global markets, differently from the post-war efforts to re-build European societies, are founded on individualism with emphasis on consumption and competitiveness with a reduced interest in collective questions. In other words, we perceive a transition from an ideology of social engagement to this new order.

Another important question in the present discussion is a relativised conception of population and necessities. Globalisation brought a movement of people among countries; consequently, intercultural cohabitation and the political pressure of minority groups gained relevance. Consequently, the approach to the problem should be changed, but it is equally important to conceive rights, duties and benefits through means of understanding the new social demands.

Foucault (2000), affirms that the welfare system cannot be defined only with the medical concepts of health and illness. 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 seen 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* in Europe. This is the consequence of the tensions caused by demands for an equal distribution of the State's resources. On the other hand, independently from the changes of context, it is important to consider that the European populations pressurize against the reduction of the acquired benefits; for example, the consistent protests against changes in the pension systems in various countries. These are delicate points on the agendas of contemporary governments, which means finding viable alternatives to maintain the standards of the European citizens, avoiding excessive burdens on the state budgets.

In the various European countries, the *welfare state* serves as background for the studies on public policies because it has a long and dynamic history and it has supported the democratic cohabitation of its populations, where the right to State health care, education, home, and the various aids e incentives are provided to the entire population. Each society is unique in its characteristics and needs, but a well-structured and stable system can be used for orientation, as epistemological tool to analyse the public policies in other countries. In our analysis, we were especially interested by the period of stabilisation of the *welfare state* in Europe, since living and health conditions of the populations needed urgent attention, like the present situation for most of the Brazilian population.

Brazil needs to establish its system of social welfare on firmer ground. From the eighties onward, with the return to democracy, the country invested in reforms for welfare extensions and modernisation, like universalising the offer of *welfare* to all social groups, regardless from the job position or income (Draibe, 2005, 2006). It is indispensible to think changes and new social demands to project or re-think the welfare system. Brazil went through considerable political changes, with them came a greater preoccupation in changing the dire conditions of social inequality in the country. Living conditions of the population still need urgent attention.

We could mention examples of efforts like the stabilization of the economy, as well as the search of social modes of organisation that aim to greater justice, participation and income distribution as efforts towards a more equal society. Another more recent example is the initiative *bolsa família* (family allowance), which besides being criticised attends 11 million families, or 44 million very impoverished people. Changes on national and international scenarios demand a renovation of the model of the social inclusion if we expect the entire society to access education and health, adequate housing conditions, work and greater social participation.

Public Policies of Social Protection and Diversity

One form of structuring the social welfare system, at the basis of the post-war European model, is the attention toward groups with special needs, in those days it referred to the attention to the population that mostly suffered consequences and losses during the war. Later, the group with special needs became bigger after the reception of other groups with different situations of inequality, the welfare passed to care for assistance and inclusion in the social texture. Undoubtedly, this approach can be accused of being mere assistance perpetuating social inequalities. However, at the same time, it supports groups with diversities whom, without aid, would have reduced chances of integration and, in some case, of survival. Furthermore, it shows how much the concept of mobile lines introduced by Foucault (2000) is applicable to practice.

The concept of diversity continues to expand absorbing other groups. In the recent past, more precisely between the sixties and seventies, racial and women discriminations dominated the scene, movements associated with these groups were granted some conquests, like women's right to work, abortion, social liberties, increased vigilance against racial discrimination, equal opportunities for different ethnic groups and more. 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, religious minorities, landless workers 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.

Since the sixties, diversity is part of mainstream political and social discussions in the Western world. However, from the eighties the influence of the social movements of the so-called minorities grew significantly. This influence can be felt in the changed political agendas of prominent political figures of yesteryear like the Prime Ministers of the UK and Spain, Tony Blair and José Zapatero, who inherited the European Socialist tradition, but instead of emphasising income distribution and economic equality, took civil rights as the main guidelines of their governments. Undoubtedly, the two societies enjoyed good economic health and income distribution was not a priority anymore; it is however undeniable that those discussions like legal recognition of unions outside the traditional family model have kept parliaments busy in the last few years.

Science too was strongly influenced by the increased attention toward social movements and civil rights, it acquired, using research methodologies, more critical and less discriminatory forms of reading texts, works of art, cultures and the surrounding reality. In social sciences, post-structuralism represented a watershed, with its destabilising reading of the mechanisms of power and control of societies and with the confirmation of the deconstruction of the philosophy of the subject (especially in Foucault and Derrida, but not only).

In this approach, the analysis of the discourse starts from power and its influence in constructing truths and social relations. Up to that point, logocentrism was dominant in the analysis of the discourse, especially in psychoanalysis, but also in semiotics and culture. It was hardly hit and, albeit keeping the word at the core, critics dismantled the certainty of rationality and symbolism. The meaning is always relative, it depends on the reading done, the latter excludes always the other readings; evidently, there is not only one exhaustive explanation (HALL, 2001). Exact sciences too were affected by the relativisation of scientific certainties and, starting from the theory of relativity and quantum physics, the dogmas on scientific neutrality and the influence of the researchers on the results were put in discussion.

Foucault (2000) analysed the structures of power in western societies and evidenced control systems coming from social care, health services to people with mental illnesses, convicts, bodies and sexuality. Care appears as assistive, but, mostly, is an instrument to confirm the structures of power. The understanding of the systems of protection and social welfare becomes essential in discussing public policies, as well as the understanding of the control generated by these systems.

In order to proceed with the analysis of the different models of welfare in the two countries considered and their influence in the social inclusion, we present data from case studies derived from our experiences in Italy and Brazil. To do this, we focus on some of the main characteristics of the two models, as well as on their development in terms of attention to diversity.

Epistemological consideration on the inclusion models

We start from the personal knowledge of the Italian system, with an experience of five years as psychologist and educator in attending children and teenagers in conditions of learning and developing deficit, which could derive from organic, mental, sensorial socio-familial and contextual problems. The educational intervention aimed especially school insertion as primary social core outside the family and privileged place to acquire didactical knowledge, but also in establishing relational competences. The socio-educational system derives from an anti-institutional model, decentralised, which means that it is carried out by social cooperatives that assist the subjects in need and, at the same time, operate in constant interaction between the community and the reality of the subject and his/her gradual acceptation.

The Italian experience is important, as it is more than thirty years old. The starting point was the work of Basaglia (2000) in the seventies, who achieved his goal with the Law 180, in May 1978, known as the law that closed the Asylums. The new relativizing approach to madness and the belief in the human capacity of free will, regardless of mental illness, are the basis of the law. Essentially, the law forbids forced admission for the mentally ill and promotes their cohabitation in the society, avoiding long periods in mental hospitals. The previous law, dating from 1904, considered legitimate compulsory admission through the recognition of dangerousness of a person for him/herself and the others established by a doctor. Law 180 shakes the power of medicine and the dogmas of the therapy, changing radically the role of the health professionals.

Basaglia (2000) put the subject and the community at the centre of the question of psychiatric illness. “Caring is everybody’s role”, this premise expects a big transformation of institutional and social roles. Madness is given equal status with reason, booth are human conditions. The sick subject can and must decide when to be refrained, personally searching for help when he/she finds it necessary. The community can and must accept these subjects in its daily life, helping and accepting them with their differences (Basaglia, 2000; Giannella, 1977).

These ideas prepared Italian society to live with difference in various contexts, among them, fundamentally important, at school. From the beginning of the nineties, the law in Italy establishes that children with disabilities must frequent regular classes. Diversity in not used as an excuse to segregate them. Furthermore, there is a structure of reception and assistance to those who are considered socially disadvantaged, it works in synergy with schools, families, labour market and other institutions. It is a networked system of assistance and social control.

Sennett (2004), despite being critical to the anti-institutional movements of the sixties and seventies, obtains important contributions to understand the development and transformations of the welfare state in different countries. His critics of anti-institutional theoreticists, especially Goffman, but he does not spare Foucault, go in two different directions: on one hand, Sennett sustains that the closing of the asylums and other total institutions happened too fast for the possibility of substitution of the institutions to provide other sheltering and supportive structures for the subjects in need. On the other hand, the author sustains that there was an overvaluation of the value of the community, or the inclusive capacity of the society to assume the assistance of these subjects, overlooking the necessary symbiosis between community and institutions.

Furthermore, many governments took advantage of the anti-institutional struggle to lighten their responsibilities with social assistance, and reducing public expenditure, this affected more than the due the subjects in need. The author mentions the Italian case as one of the few where the State destined consistent funds to create alternative receptive structures to the new demands that followed the closure of the asylums. However, this model too has its critics.

> The complex and particular needs of the ex-patients certainly did not stop existing when patients were free to leave; the number of persons in a state of total abandonment on the streets rose dramatically. Social workers had to reinvent, so to say, the bureaucratic mechanisms (Sennet, 2004, p. 159).

We disagree with many of the critics of the author, but we think of essential importance this understanding of total institutions that followed the anti-institutional movements, and how the bureaucratic machine moved facing the new needs. Starting from these historical data, we think that it is possible to re-build and understand caregiving for people with special needs, plan new policies adapted to contemporaneity, keeping always the mobile lines of the welfare state in mind.

Working with Diversity

Diversity is something present in our daily lives; many of those differences demand new answers from us every day. Accepting the diverse means being open, questioning the certainties, to contrasts, tolerance, suffering and limitations. Persons ready for this challenge result more understanding and less individualistic facing the needs of others, as well as more sensitive toward collective questions (Rodrigues, 2005). This is why the cohabitation of people with disabilities with normally developed ones is essential; they can test the educational benefits for both sides.

Many years ago, I read on an article with an unsettling definition of “undeceived”, an expression commonly used for somebody who has no more life expectancy, near to death. The author, of which I lost reference, asked himself: if a person near death is called “undeceived”, that is no more deceptions, are we all, who are feeling far from death, deceived? We could think in this terms of the expression “disable” as without abilities, without efficiency, denying the capacities of someone making things properly.

After 2002, the World Health Organization (WHO) decided to drop the expressions *disability* and *handicap* and insist on concepts like capacity and performance and strengthen the idea that, depending on the situation, everybody, with or without efficiency, can have their *performance* altered. In 2003, European year of awareness on disabilities, came the proposal of substituting the negative term “disability” to “diversability” diverse abilities, was brought forward. The reasons do not refer to the politically correct, despite recognition of the importance of monitoring at all times potentially discriminatory terms, but belong to a project of care and education for diverse able persons, the result of many years of research and action with these persons in European countries (Ianes, 2003).

At first sight, diversity seems an excessively generic term, since we are all different from each other. The idea is that diversity, or the situation of being unable to achieve a given goal, can concern everybody in any moment of our lives or in a specific condition. The point is not denying the real needs for aid for those who have a learning and development deficit, but modifying the normative image of limited, insurmountable and restricted to that of being with or without efficiency. In working to modify the normative image, we work on its fixity, which often is at the basis of the discrimination (Ianes, 2003; Cangulhem, 1990).

We consider all conditions of diversity as special needs, or needs of special educational treatment, originating from psychological, physical and sensorial limits that prevent the psychophysical development according to the age in a definitive or temporary form. At times, these conditions expect personalised attention to the single individual inside the regular class. Some examples that we witness in our work experience are needs that go from the socialisation of a foreign child with situational communication difficulties; support for a girl with impaired vision to attend her school activities; help for a child with minor neurological deficits, who cannot keep up with the pace of the rest of the class to another child who needs help for locomotion. A characteristic shared by all was the difficulty of being accepted and being seen as persons with little or no condition to overcome their physical, intellectual or behavioural limits. To assist persons with special needs at school does not only mean to insert them in regular classes, instead of special institutions. Class assistance, or in the family, requires professionally qualified personnel, and also:

a) the capacity to emphasise and interpret the needs of the subjects;

b) the ability to project and integrate group and individual activities;

c) being able to harmonize the subjects’ integration without overlooking or denying their special needs;

d) the competence to produce adequate material for different learning needs;

e) the capacity to act and adapt before the unexpected;

f) the experience to act and reflect about the task;

g) the sensitivity to balance the levels of expectation with the understanding of the limits, without acting patronizingly, denying the possibilities of growth or favouring dependence.

We could mention many more skills required, however, in short, it is necessary to have technically trained personnel, and also highly flexible and creative.

In our experience with diversity in Europe, we perceived a considerable number of people on wheelchair, with canes, dog guides on the streets and in public areas. Initially, for those who think of it as consequence of disasters or recent wars, it takes time to understand that these persons can be in all these places, because they can rely on adequate structures, buildings with fewer barriers and means of transportation adapted to different physical and sensorial conditions. Secondly, they can count with the acceptation and normalisation of their presence in society and in productive contexts. Furthermore, people with disabilities rely on an educational system of inclusion that provides an early introduction to daily social living.

Most of the people with diversity in Brazil cannot rely with professional support and early stimulation to exercise autonomy and gain independence. They do not rely on a job to support their weak points to gain confidence and play a role in the social, professional and affective life. All these people, whom we never met in the school and universities that we attend and teach in Brazil, have a lot to give and, probably, they had even more in the past, but were never encouraged, stimulated or helped to develop. This is very true if we think to the period that intervenes between school and work, as well as to the guarantee of quality of life needed for the development of autonomy for these persons. Next, we discuss the challenge that persons with disabilities face to conquer inclusion in different contexts, with the protection of their rights for a full life with quality.

Case studies of social inclusion: models and perspectives

Let us imagine a model of inclusion where a child is diagnosed and recognised as bearer of one or more disabilities after birth. This child will receive all the care that the conditions require from the early years of life: assessments, tests, surgeries, prosthesis, physiotherapy, sensorial rehabilitation and other stimuli. According to the degree of severity, the child will continue to receive assistance by specialist medical teams.

This child, just like every other child of the same age in his community, will enrol in the school nearest to home, in a regular class. At the same time, the social services of his community establish, on the basis of the available public budget and the disability, which kind of assistance is needed: in the school hours, at home or other forms in different areas of intervention. It is mandatory, schools must accept children with disabilities to enable the total inclusion of the subjects in society and their, and their families, quality of life.

Such characteristics, typical of the Italian model, show that school inclusion has a long history in this country, where the welfare state has old and deep roots. Even with the budgetary restrictions, which affect health systems in other countries too, social inclusion has strong cultural basis in Italy, and is a value in itself. Actions of inclusion have the theoretical and legislative roots that we have already mentioned in other works and above (Giaconi; Rodrigues, 2014; Rodrigues, 2007; 2005).

To provide examples of the Italian model of inclusion, we relate our experience as educator in schools, from 2002 to 2007, aiming to describe and analyse how the principles of inclusion work, or, how they happen in real life in the classroom and at the beginning of labour insertion. Therefore, we describe how the daily routine at school happens using the example of two girls in a town near Genoa: Luisa aged 14, in the third grade of secondary school and Maria aged 10, in the fifth grade of primary school. The choice fell on these two cases, among many other, partly by chance, but at the same time because of the span of the educational relation and the types of assistance: Luisa was assisted at school, Maria at home, after school. The former was attended for three months, the latter for two years.

The Italian cases. Luisa suffered a brain tumor at the age of three, it caused her severe visual impairment without affecting her cognitive capacity. The municipal social services provided an educator to assist her at school, for 12 hours a week, or, nearly half of the total weekly school attendance of 27hours. Apart from the educator, the young student had a support teacher for some hours in the classroom.

Luisa was assigned to a class on the first floor of her public school, in the town's historical centre, a building from the nineteenth century, it had staircases but it was adapted to the needs of people with difficulties of locomotion with the introduction of ramps and elevators. A member of staff had the duty to escort Luisa to her class every morning, with time this task was shared with some her classmates.

Since the assistance for Luisa was not daily, classmates and teachers showed much involvement with Luisa, helping her while she studied alone. The educator helped her in her school duties, mostly reading, but also geometric drawing and other precision tasks. Luisa did not use glasses, but magnifiers to read and write. Her profit varied from average to above average in all subjects, therefore she never needed any facilitation in the evaluations. She was very demanding of herself, she showed frustration when she received low grades. In these episodes, the educator was able to communicate with her about her feeling and her disability.

In Maria's case, family problems, economic and domestic, made the municipality opt for home educational assistance, also for 12 weekly hours. As further economic aid, with the intent of guaranteeing school attendance, the municipality provided free transports to school and back. After the morning school, the educator went to Maria's house, three days a week to help her with the homework. This intervention was a pedagogical aid and a form of social control, as Maria's difficulties were worsened in a scarcely stimulating and conflicting home environment. The girl showed appreciation for the presence of the educator, however, she showed resistance in doing the homework.

Each visit lasted two consecutive hours and Maria had little tolerance for this amount of time, she complained about sleep, general pains and at times she resorted to crying and other methods of persuasion. The intervention took place in a highly troubled environment, with a constant movement of people and loud family dinners, sometimes conflictive; this distracted the student's attention and required double efforts from the educator.

Maria's school profit was below average and she had facilitated evaluations. Her diagnostic was of length cognitive disability, with behaviour worsened by the family context and the suspect of hearing deficit. The last problem could not be definitively established because of the cognitive limitations of the girl, which interfered in the interpretation of the results of the hearing tests. When she was asked to say what she heard, or how she heard some stimuli, Maria proved unable to articulate coherently inputs and answers, which distorted the results of the tests.

If Luisa and Maria did not want to continue studying at the end of compulsory schooling, would be accompanied into the labour market. Luisa chose the Psycho-pedagogical Lyceum, to pursue a university course based on humanistic. Maria chose a vocational school to work in beauty centres, which requires the compulsory schooling and some technical training.

In the period that prepares to work, the municipal social services try to supply aid for people with disabilities. The idea of passage from a life stage to another, or from one institution to another (from public institutions for school inclusion to other ones related to work inclusion), should be well organised. Maria chose a professionalising path and was directed toward the labour Market.

People with disabilities are employed under law 68/1999, which regulates work insertion known as Norms on the Right to Work for People with Disabilities, a commission from the local branch of the National Health Service values the person. The service establishes the person's conditions and suitable activities, on the basis of the person's physical, psychical and sensorial capacities. This evaluation happens also when a person with disabilities enters a workplace that can cause risks for his/her health, limiting of restricting the person's tasks. The law allows persons with disabilities afflicting at least 45% of the labour capacities. The law prescribes access to the labour market, including training courses, as well as incentives, namely tax refunds, for companies that employ these workers. If the person is diagnosed with a temporary or final inability to work, he/she will receive public, from the company in case of a work accident.

These obligations were respected, a manager from the employment agency for disabled persons of the Province as well as an entrepreneur from a chemical industry from the same region confirmed it. Data from the employment agency demonstrated that 98% of the quotas due had been assigned. Another important element, as stated by the entrepreneur, is that the responsible social operators execute and manage "the entire project of inclusion of people with disabilities in his company without intermediation".

We found some faults in the Italian model too, for example, these workers receive only slightly more than 50% of the wage of other workers. Low work turnover is a characteristic of the Italian labour market, which causes a shortage of available workplaces. Some projects help the companies economicly, with tax exemptions, if they employ an number of workers with disabilities higher than the quotas imposed by the law. As the manager of the employment agency put it: *"this is a new frontier, currently studied, which will give higher incentives to companies that employ people with disabilities"*.

The present budgetary crisis of the Italian state, especially after 2011, undermined these projects. Nevertheless, there is some room of manoeuvre as most enterprises welcomed the obligations of law 68/99. Apart from this, the possibility to increase labour inclusion for people with disabilities relies on the social responsibility of the companies, a rather well spread attitude throughout the country.

> "Companies are more receptive than our belief. When I started working in this area in 2004, I had a wrong pessimistic idea when I looked for firms that had no obligations to listen to us. How could we overcome this barrier and focus on our goals? Practice proved me wrong, reactions are positive". (Manager of the agency for employment of disabled persons)

The Brazilian cases. Brazil too has laws on school inclusion, and quotas for people with disabilities on the labour market. Law 8.213/99, known as law of the quotas, established a quota varying from 2 to 5% of employments for firms with 100 or more workers. More recently, law 13.146/2015, known as Statute of the People with Disabilities, addressed some criticisable aspects of the previous law. Its base was the Convention on the Rights of People with Disabilities, ratified by Brazil in 2009, introducing the concept of functionality. It also establishes rules to evaluate disabilities to work with a biological-psychological-social approach, by a interdisciplinary team. The instruments of this investigation are under construction and will be applied as from 2018.

The examples provided here are of people with disabilities who work in Brazilian firms that participated to researches during 2014 and 2015. A first element, emerging from the study, is that these young workers aged from 23 to 35, invariably had to overcome barriers to be accepted at school. There are examples of children who lost years of schooling, or were discouraged to attend school because they did not have "the necessary conditions" to learn, and others who had to try eight different schools before being, finally, accepted. Often, the schools did not have basic structures to access, like ramps or elevators, other schools did not have trained personnel to accept these students.

> "in my district there are about 6 or 7 schools, all of them public, no one of them accepted me, they all talked about accessibility, to make new constructions, review some things, which were unavailable in that moment". (A., 24, physical disability, *Grebe syndrome*[1])

> "I was helped by one or two persons, few people really believed that this could happen, I started studying in a regular school". (C., 25, visual impairment)

We have the case of a school that denied the access, because the disability of the child needed, as precaution, the constant presence of the mother outside the classroom.

> "It was complicated, mine was a small private school. They did not have means to adapt the structure, but they were the only ones to accept me. No other school accepted me, my mother had to stay in the corridor, just in case something happened to me. […] this lasted throughout my school years". (M., 30, physical disability, *Osteogenesis Imperfecta*[2])

Another testimony comes from a young woman who lost her vision at the age of 15 and was advised to stop studying, as the teachers felt inadequate to teach her. She kept studying, aided by the determination of her mother, who assisted to the classes and helped her with the tasks, in a time in which computers and other technological supports were not widely available. The mother informally played the role of the educator described above.

> "My mother listened to the classes and copied everything in Braille to allow me to study. She and my brother practically attended school with me, university included. They always believed in me". (C. 33, visual impairment)

It is important to highlight that the people interviewed struggled and suffered for their inclusion, in one way or the other they completed their schooling and, in many

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[1] This syndrome results in low height, with shortened upper and lower limbs.

[2] Pathology of genetic origin, it causes frailties in the bonés and other connective tissues. There are diferente forms of manifestation of the disease.

cases, obtained a university degree. Right now, they all work. However, we assume that many families renounced attending school because of the difficulties found and the rejection toward the disabilities of their children.

Data show that Brazilian schools now accept more children with disabilities. Considering the age of the subjects, in the studies analysed here, who found barriers to their inclusion, it appears that slowly the conditions of the schools to deal with these situations improved in the last years. These data can bring some optimism to the people with disabilities, their families and professionals who work with inclusion. The passage from school to work seems to be the neuralgic point in the process of inclusion, because, once the school is over, may it be secondary, vocational or at university level, where do people with disabilities go or resort to? In the Brazilian case, there is a fracture, a gap, between school and labour market and this has a fundamental role in the difficulties in the labour inclusion of people with disabilities.

The testimonies showed that each case was governed by exceptionality, without fixed rules or legislative pre-determination. The government passed a law, number 13.005 of 25 June 2014, to universalise school for everybody by 2024. The goal established reads as follows: *'universalise, for the population from 4 (four) to 17 (seventeen) years of age with disabilities, global disorders of development and high abilities and giftedness, access to basic education and specialised educational attention, preferably in the regular school system, with guarantee of inclusive educational system, multifunctional classes, classes, specialised schools and services, public or associates.*

We may comment that this law may be slightly too vague when it says 'preferably in the regular school system'. However, there seems to be a further problem, there are no reliable data on school attendance for kids aged from 4 to 17 with some kind of disability. The two main providers of statistics, IBGE e do Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira (Inep), are not compatible, there is no way to cross-check them. The two agencies use different criteria to define disability. For example, IBGE does not gather data on global development disorders and high abilities and giftedness, the only data is on Brazilian with difficulty to see, hear or walk and permanent mental/intellectual illness. Where do we start if we do not know who are the people in need?

(http://www.todospelaeducacao.org.br/reportagens-tpe/31128/brasil-nao-sabe-quantas-criancas-com-deficiencia-estao-fora-da-escola/)

It appears evident that the related trajectories of school and labour insertion have standardised courses of action, each school or firm act according to its own criteria. The stories vary greatly from each other: in some of them all went well, in others the firm was totally unprepared to receive workers with disabilities, or where the worker was marginalised as the worker was considered unable to do the tasks; in other cases there were noble attempts to adapt to the needs of the workers with disabilities.

> "I started working in a large commercial firm in 2008, as telephone operator. In the firm they offered only Braille and no computer. […] after seven months I went to work in a large school. There I had the opportunity to work on computer, the school offered the computer but did not believe that it needed to be adapted. It took three month for my computer to be ready, with a screen reading software.
>
> My third work experience was the best adaptation; it was a technology firm. Computers were ready, I only needed to work". (C., 33, visual impairment)
>
> "Firms want workers with disabilities only to fill the quotas. But, we also have another side, when the disabled finds a barrier and does not try to solve it, he thinks it is better to leave the firm". (J., 34, visual impairment)
>
> "Talking about visual impairment made everything worse […] I went through situations where the vacancy existed when talking on the phone. When I went there the vacancy did not exist anymore". (C. 25, visual impairment)

The wage is another element of discouragement for many persons with disabilities. As seen above, if the capabilities and qualifications of the workers are not sufficiently understood, the work receives low recognition. We recorded noteworthy differences in the financial treatment, however, the most frequent complaint was about low remuneration. Besides, there is no state employment agency under the responsibility of a public entity or designed by the government, or with an acceptable efficiency; there is direct contracting between firm and worker, which causes wage inequalities among workers. One consequence of these practices is that they pave the path for manpower mediators, who earn with recruitment and selection. This situation is stimulated by the firms, which feel the pressure to fill the quotas, in a labour market that lacks in workers with disabilities.

> “I have a high level of schooling and have experience. I go to various interviews every year, they request and question many thing but always offer the same wages. Worse, sometimes they offer just a few more Reais. Who changes work to earn just a little bit more?” (C, 33, visual impairment)
>
> “My wage is within the context of my task, but I work for a company that is organised with fair wage brackets”. (J. 34, visual impairment)
>
> “Here the wage is better. There [*the previous workplace*] they paid little. They did not pay overtime there. They only let us go earlier sometimes”. (L. 26, intellectual disability)

The experiences show us, apart from individual expectations and difficulties, that there are elements recurring in each model, in inclusion as well as in exclusion. The Brazilian model is still subject to the approach of the one who receives: school or firm. We used the term exceptionality before, to describe the above uneven situations of inclusion, as there is no established procedure in receiving workers or students with disabilities. Improvisation seems to denote the stories of the inclusion of these persons. The legislation does not provide details on the inclusion processes, and the institutions responsible for each stage, and more. Our desire is that this could be the departure point of a journey that in time will be more receptive toward the needs of the people with disabilities.

The Italian model shows an higher definition of roles and procedures. The subjects know, or learn at an early stage, whom to contact for their needs and whom to talk to. Since their birth, children are oriented to medical, rehabilitative and educational care, helping development and avoiding losing precious time to stimulate their capacities. Regardless of what the future holds for the person, or his/her choices, people receive support throughout the journey, this is an element of equality for all citizens, no matter the good or bad disposition of an individual or organisation.

Undoubtedly, the role of the context passes through raising awareness for the necessities of different groups and the ensuing changes of their public perception. We analyse below the inclusion and training of people with disabilities in organisations, providing some extracts from a research conducted in a large industrial organisation in southern Brazil, which has a successful scheme of training perspective employees with disabilities.

The Project of Inclusion of disabled people in this firm started in a stable form in 2009, to fulfil the legal requirement of accomplishment of the 93rd article of the affirmative action legislation, which demands a percentage of workers with disabilities in large organisations.

A team of workers of the Human Resources of the company (HR) developed the proposal of a specific programme for work training and inclusion, after researching with institutions that include disabled people and benchmarking firms that have experience in this field in the region. The Board and main directors accepted the proposal.

The first step was to give talks, held by the team, to make managers and workers of the firm aware of the importance of including disabled people. In doing so, contents of awareness as well as information of the types of disabilities were analysed.

This first step unlocked other actions and adaptations in the firm, which changed substantially the way it looked at work. A programme that had been created for affirmative actions, was transforming the organisation that began to get involved with the whole process of inclusive work – from selection, integration, orientation, adaptation, development to retention of disabled workers in the firm.

The company started to change some processes to improve the understanding and adaptation of the working conditions. The process of selection involved the family members. They were also involved in training and adaptation schemes. The process co-opted also sectors such like health and safety, in a role previously covered by the HR department. This process was essential in adapting the job places to the needs.

The training scheme was so successful that the company passed from 37 workers with disabilities in 2010 to 108 in 2015. Figures provided by the firm show that two third of the workers with disabilities are intellectually disabled in addition there is another small number of disabled workers with disabilities related to other origins. This observation was useful to enlarge the interest of the organisation to hire more workers through the learning program. Since then, the firm has promoted five more groups (one per year), each one preparing from seven to ten trainees. Up to this moment, the firm has hired most of the participants; this factor indicates the success of the project of inclusion. A professional from the company stated that the training programme is excellent for the company and that the staff adapts to receive the trainees.

Before the beginning of the training course, the company gives the availability of courses for trainees using channels like web sites, newspapers, associations and similar. The selection of the candidates happens through interviews with the training instructor, who will accompany the learning process, the HR analyst and the psychologist responsible for selection and recruitment.

There is a programme of integration training for trainees, legal representatives, teachers and members of the companies that signed the training contracts. Trainees have also some benefits like transportation vouchers, medical assistance and discounts on pharmaceuticals. The integration phase aims to clarify all that will happen during the training period, it also provides a good environment for the training, and good information for the decisions that trainees and their families will have to take.

The next stage is entering the work life: in the last part of the course job places are confirmed after practical training experience in the company. The family, or persons legally responsible, the worker with disability and the sector that will receive them must agree on all points of the contract. Once the agreement is reached, HR starts the legal procedures to employ the new workers. The approved workers are employed after legal procedures as admission exams, opening a bank account for the training support salaries, providing documents, and more.

Finding a place in the labour market was a desire common to both people with disabilities and their families. They perceived this opportunity as an open door to a more steady working life. All interviewed trainees had the expectation to stay in the company as permanent workers after the end of the course.

Even if for many of the participants the course will be followed by a trial period that may not end with full employment, they are very aware that this is a door that opens onto the real labour market. A course like this provides a much-needed fill for the gap, between school and work that so often occurs for the youth with disabilities, who after leaving school stay home.

Simple and routinely actions like walking the street, catching a bus, and other activities can be challenges depending on the kind of disability and the economic conditions and lifestyle of some subjects. Some of the interviewed trainees reported that the course made them meet new people, and made them more independent. Going out and returning home on their own made them discover that there is a world outside their homes. Discovering new routines. Some reported that they had to convince their parents to let them go to the course alone, and managed to do it.

The improvements reached home too. One trainee said that he learnt from the teacher things like cleanliness and organisation, what he learnt in the course he transferred to home. Dishwashing, mopping the floor and more. The professionals see the results in a similar way to the one related by the trainees; they include increased responsibility and involvement on the job, apart from the specific knowledge of the working process of the organisation.

According to a manager of the public inclusion programme, the firm gains because there are no other courses that prepare trainees specifically for the working process of the company. There is already a legal obligation to have trainees at work, and it involves costs. Therefore, it is better to train them properly. The person with disabilities obtains an opportunity to qualify and work in formal jobs and stops depending on the State and contributes to society. We may add to this, as we saw in the statements made by the trainees, their Quality of Life makes a leap forward.

Work as instrument of emancipation

Thinking about adults with disabilities leads us to reflect about a scenario made of lights and shadows, which wraps the path toward adulthood of the persons with disabilities. Scientific literature (Goussot, 2009; Dettori, 2011; Giaconi, 2014) is increasingly focusing on which paths should be taken to contrast the static image of the disabled subject as eternal child, therefore raising awareness supporting structured, coherent and dynamic paths, which may lead to complete a trail under the sign of the Quality of Life of the person.

At the end of the school cycle, young persons with disabilities and their families are effectively in danger of not finding an adequate integrated system that facilitates widening the spaces of autonomy, participation and integration in the community. For some youth, leaving school means reducing the social network, the opportunity to live in contexts other from the familial one, as well as the repertoire of recreational activities and free time.

The phases of transition from school to working insertion, from home to other living solutions, for example, after the loss of the family members of reference, must become moments oriented and thought over time and “in time” so that they may become the springboards toward adult life and the realisation of the person with disability. In fact, Lepri says “we become adults starting as children” (Lepri, 2004, p.16), thanks to a project of life that fills and restructures itself in space and time, is consistent with the different phases of the cycle of life and the uniqueness and specificity of each person with disabilities and the community.

The path to working inclusion sneaks between lights and shadows: starting from the remarkable legislative framework for the right to work for the disabled (Law 68/1999). It marked the change from the principle of mere assistance to targeted employment respecting the working potentialities of the persons with disabilities; data are not always comparable but show that occupational levels are still unsatisfactory. Paternò uses the 2004 International Labour Organisation report, which shows that 52% of disabled persons in working age does not appear on the job market in Europe (in a total population of 37 million disabled). In Italy, ISTAT outlines an occupational rate of 26.5% in 2004 (out of a 2 million and 824 disabled), in 2005 ISFOL-PLUS reported an occupational rate of 38, 1% (on 526 thousand disabled) compared to the 63.4% of the overall Italian population (Paternò, 2009, p. 293).

While in Brazil the problem begins at school, according to data by INEP (Instituto Nacional de Estudos e Pesquisas Educacionais Anísio Teixeira), the number of students with disabilities in the regular network of school grows every year. While, in 1998 there were 43.9 thousand disabled students in public and private schools, in 2003 this figure grew to 144.1 thousand, in 2004 it went to 184.7 thousand, this meant a yearly growth of 28.1%. Consequently enrolments in special schools for disabled children fell 87% in 1998, and 65.6% in 2004. (Available http://www.inep.gov.br, accessed on 20/01/2015)

However, the 2010 Census (Instituto Brasileiro de Geografia e Estatística) affirms that the youth that ends the school cycle in Brazil are a minority, as 61% of the youth with disabilities have no access to school or attends only the first two years of the elementary school. A minority indeed, but also an important group, because it somewhat means that the country began to accept youth with disabilities. Above all, this means that this group represent the resilience and persistence despite all the difficulties.

(http://biblioteca.ibge.gov.br/visualizacao/periodicos/545/cd_2010_educacao_e_deslocamento.pdf, accessed on 20/01/2015).

The case above mentioned is an illustrative example, which goes beyond the requirement of the Brazilian legislation for all companies with more than one hundred employees to have 2 to 5% employees with disabilities. The example is located in that essential gap that needs to be bridged, the one existing between school and work. In the words of a coordinator of the Ministry for Employment in the region where the company is located "several municipal structures in disadvantaged areas of the cities (in southern Brazil, author's note) try to bridge the gap between school and work. If there is not a passage between work and school, the person goes back home and it becomes more difficult to rescue the person to work and be participant in the society".

Furthermore, in a cultural and economic scenario marked by the crisis and the general increase of unemployment, the critical issue of work is even more remarkable for disabled adults and in particular for women with disabilities (Colombo, 2007, p. 29).

The complexity of the argument commands a wider conceptualisation related to social inclusion and the Quality of Life of the adults with disabilities (Schalock e Verdugo Alonso, 2002; Giaconi, 2014). This contribution will focus on work as the privileged way to recognise and be recognised as adults and therefore assuming an adult identity, in terms of participation and active citizenship.

Work, even in its ambiguous aspects made of critical issues and potentials, limits and self-realisation, remains of fundamental importance in the life of people (Lepri, 2009, p. 19). An effective path of working insertion leads to improve the Quality of Life of the person. Certainly, work allows us to meet our limits and demands new modes of communication, different relational forms, responsibility and co-responsibility and a path toward forms of self-awareness (Montobbio e Lepri, 2000).

This is a delicate matter, therefore, we must reflect on this critical point using all the possible pedagogical sensitivity to avoid falling into interpretative rigidity, opening instead to desirable settings. In this direction, we report some challenges for working inclusion, which pedagogy has to meet, which we will see in the next paragraphs.

In meeting with the themes of disability on the workplace, the first critical issue on the way concerns the collective imagination on these two concepts, as single issues or together. The first CENSIS report of 2010 highlights a generalised underestimation in the perception of disability: the motor disability is overestimated while sensorial and intellectual disability are underestimated.

In the texture of the collective imagination, a partial imaginary about the person with disabilities dominates and regards the stereotype of the eternal child. These non-perceptions involve activating relational styles, which are often unsuitable for adult relationships, as they are connected to paternalistic and infantilising traits.

Descending to the connection between disability and work, we often remain anchored to the vision of work for disabled subjects as a mere instrument to rehabilitate psychical disorders, with finalities of containment and social control, where welfare logics forego educational instances. Work is much more than this.

Therefore, the first challenge is to reinstate what Lepri (2003) defined the "needs of normality". Work belongs fully to these needs. Work represents an essential value for the realisation of everyone, including persons with disabilities. An auditor from the Labour Ministry, responsible to implement the inclusion law at work came to the point of saying that companies want "blind who can see, deaf who can hear and physically disabled who can walk".

Work belongs fully to these needs. Work is at the basis of people fulfilment, including people with disabilities. We have to imagine ourselves in a space/time inhabited by desires and dreamy expectations common to all who dream from childhood what they will do once grown up. They may think and become, foresee and desire to be fire-fighters, doctors, and door attendants or be mothers or fathers, all these are not casual events. Surely, this is followed by the construction of a path that is balanced between expectations and abilities, efforts and mediation, demands and offers, limits and possibilities, action and training.

These normal events reactivate "the need of the normality of the role". If people do not have a role, the possibilities of connection with social complexities disappear. Persons with no role have no rights or duties and never enter with full title in the game of relationships of the people who populate a society. Persons with disabilities are often exempted from assuming roles, therefore from rights and duties, and from exercising responsibilities. Young disabled persons, who never assumed responsible roles in their educational stories, will find many difficulties in their working insertions (Boffo, Falconi and Zappaterra, 2012).

In the dimension of the partial imagination, the absence of planning of family and teachers rules go jointly with the same absence of the person with disabilities. The lack of a project affects the immutability of role and social dimension, while social role and choice are essential to enter the adult world, as we will illustrate in the next paragraphs.

The life project is a collective effort (Pavone, 2009, p. 71), family and educational agencies work with and for the people with disabilities, inserting them in living and relational stories and foreseeing the achievement of the possible autonomies starting from early childhood, with a constant reminder, as we will see, of micro and macro-planning.

The second challenge and strategic line concern the necessary support to re-think the working dimension as an event that involves the identity of the disabled person, or of any other person. For the disabled person, as proved by recent research, the working practice becomes one of the main devices to construct identity: it incorporates self-perception, helping to create and strengthen it.

Work strengthens identity but also belonging to an adult community guarantees to find paths to autonomy and recognition. All of this activates the necessary processes of adult socialisation, economic independence, autonomy from the original family and, mostly, affects the social and civic role of the person with disabilities, connoting, in this view, as a great *emancipatory value* (Zappaterra).

Therefore, the walk on a path of identity planning and social recognition gets underway, toward the contribution that it can provide to the working community of belonging: the more an individual feels integrated into professional contexts and relationships, the greater become the possibilities to be recognised and valued (Chicchi, 2001). Work becomes the potential regulator of inclusion.

We need to overcome the concept of orienting the disabled person to work in a frame dictated by the use of technicalities aimed to teach just a single competence. Practices that keep into account the assumption of the role and the global person produce better results (Borkowski, 1988). The problems that affect working insertion most are not so much linked to performance, they rather concern inadequate relational modalities, which include difficulties in self-perception in assuming the working role. To grow up, we need to experiment roles, have responsibilities, do things alone and respect deadlines. Persons with disabilities will perceive the recognition of their adulthood, especially in the interacting, reflected in the image and expectations that others place on them. This will make them acquire more competences and adequate behaviour. The nature of the relations that we start is fundamental to strengthen our identity, but also to share significations, which will operate in the triangle composed by disabled person, workplace and all other subjects who act as mediators.

A huge educational responsibility belongs to the school and to the community of belonging of the young disabled; in fact, we should find in them the pedagogy of roles, which allows new experiences beside the ones in family, school and workplace. Personal identity could configure as the result of all the roles that a person interprets – the acted roles – socially recognised; these roles can produce significant and useful changes on the way to adulthood. Nevertheless and too frequently, experience gives back a suffering image to the person with disabilities: a plural identity is denied, so are perspective future roles, while identity becomes mono-identity (belonging to the dis-abled). Furthermore, we do not trust the person with that competent identity whose competence derives from an appreciating glance and context, or better from the ability of seeing in the other unusual skills and talents, planning pro-active and not-handicapping situations (Caldin et al., 2009, p. 253).

A fourth challenge lies in the possibility to strengthen the concept of work as tool of emancipation, not only as tool of psychological rehabilitation.

In the past, work was used in the *rehabilitation* of psychiatric diseases, in the attempt to confine the patient interned in an institutionalised environment with the goal of keeping social deviance under control. The importance of work was initially recognised for the rehabilitation of mental diseases in a time where the disabled person was considered incapable to look after him/herself and, therefore, subject to *assistance*.

In the 1920's, work therapy configured itself as a mode to occupy the time of the sick and prevent inactivity-related deterioration. The educational goal was to structure the day, giving rhythm to the time of the disordered life of the psychotic subject. Work therapy, criticised for the closure within the institutional context, left its place to occupational therapy practiced in asylums and protected laboratories outside, performing repetitive activities for outsourced firms. We begin to see the possibility to perform a working activity with a rehabilitating goal linked with the recovery of social, relational and working skills. At the end of the 1960's, the movement started by Basaglia, besides having generated a reflection on these themes, gained credits for introducing interesting experiences also in the field of work, they included founding the first cooperatives and many interventions of social and working rehabilitation operated by local agencies. Psychiatry of those days widened the scope beyond institutionalisation and accepted educative instances: changing the viewpoint of mere assistance to a view of a global taking in charge and quality of life, which overtakes the search for abilities as *quantum* and coincides mostly with the functionality of the role:

- the person as he/she lives and works,
- what is his/her recognised role in society.

Thanks to work, persons with disabilities obtain the opportunity to recompose their own image, the intra-psychiatric and the socially interiorised one, which is the one given back to the others. Working means introjecting the role, recognising the role of the others and changing the quality of socialisation (Montobbio, Grondona, 1994).

The Services of Integration at work need new perspectives: knowledge, potentials and needs of the subject and of the firm: management of personalised paths of working integration, promotion initiatives to raise awareness and collaboration among agencies. Working with networks is the pivotal strategy: institutions, local resources, coordinating life plans that consider the subject and his/her living context. Harmonisation of modes, time and space.

The first perspective concerns the creation of new devices for skills assessment of disabled persons, paying attention to what there is behind competences, explanation of beliefs, convictions, and values of the disabled person on the workplace. This perspective enables to intervene *on the job* during phase of working insertion, going toward restructuring eventual convictions that could limit the person's performance in the professional context (Hitchings et al., 2001; Yanchak et al. 2005). In fact, disabled adult workers have inadequate professional beliefs, which could bring difficulties of adaptation or cause the failure of any form of working insertion.

In this way, the University of Macerata developed a *Professional e-portfolio,* which is general or specific according to specific professional path. This structure accepts material, meaningful experiences, experiences at risk to be fragmented and thoughts of the persons with disabilities. The aim is to portrait the picture of being professional in the working contexts.

The second perspective concerns a new proposal of "training in action" for people with disabilities in working contexts. The approach of French authors Vinatier and Altet, contextualised in the Italian system, concerns the Professional Didactics (Vinatier, Altet 2009). It allows the analysis of a professional practice, to merge all action plans, the technical and the relational ones, which belong specifically to a profession related to the contexts and to the specific organisational concepts of the working reality where the person with disabilities belongs.

Considerations

A manager from the private sector cannot disregard entirely this chapter; these questions do not concern exclusively public administration. The chapter refers to public policies but there is also the example coming from the private sector. The private sector managers could ask themselves on how much the education of children with disabilities has to do with their business. We want to challenge or at least unsettle this assumption. The convergence on the contents developed will lead our discussion.

Firstly, the discussion on the passage from the *welfare state* to *welfare mix* indicates a global trend; the countries already experience the impossibility to maintain the previous systems, which may derive from political options, or from the present economic situation. This means that the partnership between public and private sectors in social policies leaves the handbooks of administration as *best practices*, and enters real and daily practices in companies and corporations.

Secondly, the lack of education of people with disabilities in Brazil essentially means that a considerable part of the population is left on its own device, without stimuli and development. We do not refer only to the poorer population, also families with medium and higher economic situations often desist from stimulating their children, as they cannot rely on adequate aid for their needs, the burden becomes too hard to sustain. Persons with disabilities end up marginalised because they cannot rely on an adequate structure and logistic support at home and at school, abandoned in their development, without stimuli and, therefore, with little chances of social insertion. Clearly, there are honourable exceptions, which apart from being exceptions, should not be exceptions.

Companies can benefit from people with different abilities when they enter the productive age only if they have been encouraged and helped in their development. There are classic examples of deaf workers in industrial plants with high noise levels, as well as persons with autistic traits in job places that need high concentration such as installing small electronic components, and there could be more examples. Social insertion means that interacting every day with other people, affective involvement and the exercise of sexuality are essential for everybody, regardless of intellectual and physical development. By segregating this slice of the population in special schools and institutions, we condemn them to live a “special” life, “customised” in a fashion often dictated by preconceptions on their potentialities and the targets that could be reached.

On the other hand, there is a life based on stereotyped patterns, below dignity, in other words, the infantilisation of these people on the assumption that they are incapable to understand and choose their future. They become used to dependence and to patterns of relationships where the constant demonstration of their limits prevails. Perhaps, this is the origin of the stereotyped image of the person with disabilities as a person who does not respect rules and behaves in a bizarre way.

At the basis of the *welfare* is the project of justice of a country for its population, this is the respect that every government pays to its citizens (Sennet, 2004; Esping-Andersen, 1990). Welfare's multifaceted respect links with many spheres of the collective life. Firstly, it is related to the basic living conditions of the population, like housing, sewage and general infrastructures that, as we know, are very precarious or, at least, unevenly distributed. Secondly, it is associated to health and assistance provided by the State, to aid the temporary or permanent limits and deficits of the citizens; in Brazil, this aspect of the welfare is precarious and sometimes non-existing. Thirdly, it associates with education and training to work that often depend exclusively on the private initiative. These elements together leave the Brazilian young population with low levels of education and general knowledge, while practical education for living and working remains very insignificant. In addition to the above constitutive problems that originate from these shortcomings, we find also considerable stories of familial and social disintegration, among other consequences that we could list. This is the necessity, the *anaghi* that should move Brazilian society toward a greater equality in its population, to include all the strata of the society in an adequate level of social life. If we think in terms of diversity, we can affirm that precariousness is still prevailing. Education for people with disabilities, as already mentioned, is still mostly devolved to special institutions. These persons have no access to normal living; they are not prepared to social cohabitation, or have a productive life.

We all suffer in this picture; Brazil turned into a society that is increasingly unequal and violent. Companies lose financial and human capital having to select and train workers with little notion of the reality of work that often, despite of the efforts, never achieve the desired levels. A meaningful part of the population continues to live without the minimal conditions of hygiene; safety and protection, apart from having few resources and alternatives to change their lives. We have a legion of "invisibles", people who are not registered and do not access any kind of social participation or active citizenship. Can we ignore this need for a change? This context affects Brazilian industry and the possibility of an effective and stable growth. Human resources policies based on the rotation of the personnel, low salaries, low qualifications and weak involvement of the workers in improvement programmes of the companies are practices that determine an intermittent growth of the companies (Rodrigues, 2000).

Sennett (2004) identifies three pillars of respect in the present society, to discuss public policies and welfare systems: Making something of oneself, taking care of oneself, and helping others. If absent, these pillars or principles cause personal dissatisfaction and social injustice. According to the author the road to fulfil these principles passes forcibly through social recognition of diverging results and the acceptation of dependency, apart from active participation of the people to define public policies and systems of protection. .

> "[...] I can say that self-respect based on work, in professionalism, cannot alone cause reciprocal respect. Fighting the disease of inequality in society cannot alone cause reciprocal respect. In society, in particular in the welfare system, the problem is essentially to understand how the strongest ones can exercise respect in relation to those who are destined to remain weaker". (Sennett, 2004, p. 256-257).

This contribution does not have the answers for such a complex theme. Starting from the genesis of the welfare state and the *anaghi* that caused it, it pretends to use the concept of mobile line as the key for the interpretation of the changes of our times. These changes, as we saw, originate in part from the economic trends that reduce the availability of benefits, but also from the new necessities of minorities and diverse groups, which started to influence the discussion on public policies. This chapter intentions were directed to involve public and private administrators to achieve together labour policies, which would include diversity via the analysis of authors and themes rarely used in administration. If the global trend is toward the synergy of public and private, we might learn from experiences of other countries that face or have faced similar situations, benchmarking the above-mentioned experiences could provide valid epistemological tools for analysis and planning. Especially in countries like Brazil, where welfare is still a project under construction, the private sector can have a fundamental role. Therefore, it is essential to agree on the meaning we give to respect, community and inclusion, so that we can define which project of social justice and the QOL derived from it, that we want to follow.

The interviews in the Brazilian context showed us, from different sides, the level of involvement of the participants to the Programme of Inclusion. Inclusion eliminates inequality and allows entrance into consumption, non-inclusion jettisons an important part of the society because of limited resources, data from IBGE (Demographic Census 2010) show that nearly 45 million Brazilians have some kind of disability, what kind of society is one that does not allow to its vulnerable population to grow stronger?

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, intellective 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 manageing 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.

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