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Research paper

# Life project, peer counselling and self-help groups as tools to expand capabilities, agency and human rights

## Projet de vie, conseil par les pairs et groupes de self-help : des outils pour développer les capabilités, la capacité d'action et les droits de l'homme

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### ARTICLE INFO

### ABSTRACT

The aim of this article is to present the life project as a relevant and comprehensive tool towards expanding capabilities, agency and enforcing human rights for persons with disabilities. The first part analyses the theoretical elements common to the frameworks of the capability approach and the human rights perspectives, which are omnipresent at the implementation level in tools such as the life project, peer counselling and self-help groups. In the second part of the article, the relevance and the limits of the life project, peer counselling and self-help groups are examined.

### RÉSUMÉ

Le but de cet article est de présenter le projet de vie comme un instrument détaillé pertinent pour permettre aux personnes handicapées de développer leurs capabilités, leur capacité d'action et le respect des droits de l'homme. Dans la première partie, nous analysons les éléments théoriques qui forment le dénominateur commun des cadres que nous utilisons, comme l'approche par les capabilités et les perspectives des droits de l'homme, et qui sont

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omniprésents dans la mise en application sur le terrain au travers des outils que sont le projet de vie, le conseil par les pairs et les groupes d'entraide (*self-help groups*). Dans la deuxième partie, la pertinence et les limites du projet de vie, du conseil par les pairs et des groupes d'entraide sont examinées.

## Background

The capability approach (CA) (Sen, 1999) diverges from the traditional conception of disability, which is based on a medical approach and limited only to providing cure and assistance (Mitra, 2006; Dubois and Trani, 2009; Trani et al., this issue). Using the CA perspective to decipher the social barriers and prejudice that exist towards persons with disabilities also entails placing the person at the centre of the decision-making process and viewing him/her as a crucial actor in the rethinking of both policy objectives and service implementation (Bellanca et al., this issue; Biggeri et al., this issue). In other words, the CA complements the social disability model based on human rights (Borgnolo et al., 2009) – which focuses on the social and environmental conditions that limit the access to goods, rights and services. By viewing the person with disabilities as the main actor in his/her own life, the CA encourages the individual to re-gain his/her freedom and thus transition from being a passive recipient of policy decisions, towards becoming the major player in defining his/her needs and desires and determining the ways and means most suited towards achieving their fulfilment.

As explained in previous articles in this issue, various "dis-capabilities" that a person develops (Bellanca et al., this issue) depend on personal conversion factors, on environmental factors and available resources (economic conditions, resources availability, institutions, services in the area, etc.) (Trani et al., this issue). These factors – known from a CA perspective as socio-environmental conversion factors (Sen, 1999) – encompass a whole series of environmental circumstances, which facilitate or reduce a given achievable functioning of a person on the basis of his/her capabilities on one hand and social norms, infrastructures, etc. The Convention on the Rights of People with Disabilities of the United Nations (CRPD, 2006) has re-defined the disability model within a human rights framework, promoting the removal of factors which impoverish society (obstacles, barriers and discriminations) and created a new impetus to move towards equal opportunities and non-discrimination, through self and social empowerment (Oliver, 1996; Griffo, 2008). Therefore, the definition of disability in the articles of the Convention is a clear indication of the need to shift the focus from the individual to his/her relations with society (for details on this aspect see Lang et al., this issue).

Within the perspective that the CA complements the social disability model based on human rights, Biggeri et al. (this issue) have identified three instruments, which reinforce each other, that can enhance the persons with disabilities' capabilities: the life project, the peer counselling and the self-help group.

The aim of this article is to focus normatively, from a theoretical perspective, on these three instruments – the life project, peer counselling and self-help groups – i.e. as they should be having in mind the Italian regional systems.

The life project involves a process of self-consciousness, which helps to define the aims and aspirations of the person with disabilities and to explain them through a coherently tailored project. This process enables the person with disabilities to analyse his/her condition as well as to become aware of the individual and social impoverishments that are a consequence of a confluence of conditions. As we will see later in details, this process, based on individual and social empowerment (Griffo, 2006), requires effective and on-going participation of the person with disabilities (of the caregiver in the case of very severe forms of mental disabilities) in the decision-making process and in the demand for support from public institutions. Peer counselling and self-help groups can have a relevant role in the process of elaboration of the life project, by encouraging the development of awareness with regard to the person's own condition and by fully developing individual support, knowledge of resources

and of services in the area. The individual and social empowerment process attempts to build active citizenship, which is closely linked to individual and collective capabilities (Dubois et al., 2008).

Although it is not the focus of this article, it is important to open a parenthesis and to acknowledge that the authors of this article have conducted several researches in Italy on the application of these three instruments. In particular, in the Calabria Region, Barbuto et al. (2007) carried out several researches on the relevance of the life project, peer counselling and the potential role of self-help groups and experienced the role of peer counselling themselves. While, in the Tuscany Region, on the one side, Bonfanti and Biggeri (2010) analysed a successful practical experience of life project for persons with severe brain injury. On the other side, the team conducted by Biggeri and Bellanca (2011a) investigated through focus group discussions, in-depth interviews, and other qualitative methods the role of the life project and of independent life. Through an online questionnaire, they collected the opinions of different stakeholders on the potential of the full introduction of the life project and peer counselling into the Tuscany regional system (Biggeri and Bellanca, 2011b; see also Biggeri et al., this issue). Parts of these researches and experiences are reported in this article with the aim to enrich and to give a practical basis to the theoretical analysis.

Having pointed this out, the structure of this article is divided into three sections. In the second section, the theoretical elements that link the CA and the human rights framework with the life project and other tools are analysed. While, in the third section the relevance and the working boundaries of the life project, peer counselling and self-help groups are examined. In the conclusions, the main findings are discussed.

## The life project, peer counselling and self-help groups as instruments to expand capabilities, agency and enforce human rights

The concept of disability put forward in the CRPD of the United Nations can be linked with the CA and should lead to a redefinition of both the tools and procedures used to assess disabilities (on the basis of articles 1,3,5 of the Convention; Griffo, 2008) and of the services that promote inclusion[1]. It is evident that any proposal based on the CA and on the social model linked to human rights presupposes a reconsideration of traditional welfare instruments based on narrow views of social protection, and moves towards looking at well-being, social equity and inclusion mechanisms (Griffo, 2010).

This shift represents a revolution, which starts when various subjects accept the idea that disability is a social relationship, not only a subjective condition. People can move on a wheelchair, find their way with the help of a guide dog, communicate with the language of signs and thus not experience disability, on the condition that the world in which they live makes space for and accepts these features. It is not a mere coincidence that the CRPD and the CA underline the fact that persons with disabilities represent just one of the possible diversities that can be found in human beings. Hence, rather than focusing on rebuilding a condition of pre-defined psychophysical normality (as it is often done in medical rehabilitation, with interventions that may yield no results or lead to therapeutic obstinacy), people need to have the possibility to enjoy rights, fundamental freedoms and capabilities that they value. In other words, people with different disabilities may require different kinds and quantities of inputs in order to experience well being (Sen, 1999; Mitra, 2006).

Taking this perspective, we have to add the notion of enabling or "capacitating" to the more traditional concept of "rehabilitation". Rehabilitation is achieved when the person gains back a lost functionality of the body, whereas enabling is synonymous with the development of new abilities, starting from the psychophysical conditions of a person. In fact, functional diversity (due to impairment) is just one of the person's features (Palacios and Romanach, 2006), which together with all the other features, defines the capabilities of a person (A-capability), opportunities (O-capability) and potential (P-capability) (see Bellanca et al., this issue). If we would describe the athlete Oscar Pistorius merely as a person who does not have the use of his lower limbs, we would not be able to understand the empowerment process, which allowed him to become a world-class athlete (200 and 400 meters).

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[1] The Convention divides habilitation and rehabilitation (art. 26) to that related to health (art. 25).

Furthermore article 26 of the CRPD is clear in confirming: "States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services". Services and programs should "start as soon as possible" and should be based on "a multidisciplinary evaluation of the needs and points of strength of the individual"; they should sustain "the participation and the inclusion in the community and in all aspects of the society", be "voluntary (. . .) and available to people with disabilities in places nearest as possible to their community". So the objective is clearly not just to 'cure' anymore, but also to sustain an independent life and promote inclusion within the community (art. 19); not just to provide assistance, but also to facilitate personal mobility (art. 20) functionings and capabilities.

This approach changes the idea of care through rehabilitation, ruling out any form of segregation and institutionalisation, which can lead to serious violations of human rights (OHCHR, 2007): in fact the CRPD recognises "the same right for all persons with disabilities to live in the community, with the same opportunities to chose as the other members".

In other words, embracing the capability perspective in disability studies means to acknowledge that policy maker's interventions must be aimed at the expansion of individual and collective capabilities (including social empowerment) and therefore, that they must promote the process of exaptation of the person with disability, i.e. his/her pathway of creative adaptation (see Bellanca et al., this issue). Hence, instead of certifying if a person has a disability and classifying the latter, the CA focuses on the causes of vulnerability or on the difficulties a person faces in order to achieve his/her well being/well becoming. In fact, the CA, like the social model, looks at the possibility of changing limitations into resources and inaccessibility into access (entitlement) starting from rights but giving importance to the individual's experience, values and aspirations.

Consequently, "the thesis according to which biological data determines a person's destiny, and that opportunities are distributed depending on the gender to which the individual belongs, are rejected" (Barbuto et al., 2007, p. 27, our translation).

The philosopher Martha Nussbaum has effectively used the verb "to flourish", term rooted in the aristotelic tradition, in order to define the multiple possibilities through which each person can achieve fulfilment (Nussbaum, 2000). In circumstances such as disability, the life project represents the pivotal instrument, which allows the person to focus on the main aims of his/her life, according to his/her needs, values and aspirations. At the same time, it can represent an operative tool that enables the individual to plan the access to public and private services through a process of matching (see Biggeri et al. this issue).

More generally, projects geared towards the achievement of a specific goal attempt to enhance one of the most important elements for all human beings (disabled or not), namely the one linked to the concept of agency. In fact, each individual tries to regulate his/her own behaviour by defining a series of operations, which enable him/her to reach a potential desired condition. Agency is essential in order to exert one's participation and to affect political choices. In fact, it permits individual participation in economical, social and political actions, and it also lets individuals take decisions as active agents and not as passive recipients of medical treatments (Ruger, 2007).

It is thus important to remark that the process by which choices are made by the capable agent is even more important than choices themselves. In other words, it is relevant to internalise freedom of choice through the choice process, and not through choices themselves. While the capacity to aspire relates to the aspiration as such, the capability to aspire is connected with freedom to aspire, which entails examining the process behind aspirations. Therefore, it is not just a question of opening up multiple opportunities to persons with disabilities (even if this can be the starting point in case of severe deprivations), but – amongst a set of limited and achievable choices – to develop their capability to aspire through their involvement in the decision-making process.

Empowerment is the essential requirement of agency. It is important to note that the former does not imply the mere strengthening of individual capabilities (i.e. capacities and opportunities which refer to the emotional, perceptive, intellectual, behavioural, informational aspects of a person's life), but also the social strengthening of acquisition of power from the other or social empowerment (training about human rights, lobbying, knowledge of laws and resources, capacity building, institutional building).

By enhancing agency, empowerment, and giving importance to the values and choices of the person with disability (or of his/her caregiver), the life project, consistently with the CA, contributes to transforming the person with disability from a passive subject into an active one, overcoming the limitations of the previous explanatory models of disability.

It is important to note that, in spite of being strongly recommended both for people with disabilities and their caregivers, the life project cannot be compulsory. Its elaboration requires strong motivation and commitment that enables the person to believe in his/her capacities and in the possibility of achieving the identified goals (see next section for details). Children and adults with mental disability must be given the opportunity to participate in the elaboration of their own life project, even if their contribution may only be limited to given aspects and to a certain extent.

We have argued elsewhere that a person's capabilities depend on other peoples' capabilities (Sen, 2007). The actual and the perceived degree of such dependence differs according to the person considered. We have defined these capabilities as E-capabilities (Bellanca et al., this issue), stressing that they acquire a particularly important role in the well-being and well-becoming of children and people with severe mental disabilities. Also, it is evident that collective capabilities (Dubois et al., 2008) are very relevant for human beings in general, and for people with disabilities in particular, since by influencing social and environmental factors they may expand their opportunities. Actually, as highlighted by Evans, some choices have a collective rather than an individual nature (Evans, 2002). Furthermore, even when a person is able to draft the project on his/her own, it is essential that s/he confronts and shares her/his views with another person especially if authentic sharing is possible with the latter (Canevaro, 2007, p. 17).

Ensuring appropriate support to the parents of a child with disability generates long-term positive repercussions on his/her well-being, and helps him/her to become an active citizen with benefits for his/her-self, the family and the community. According to the field interviews (Biggeri and Bellanca, 2011a), there is a close correlation between the strengthening of parents' capabilities and the expansion of those of the child. Therefore, encouraging and recognising the efforts and reactions of the parents from the very onset entails the creation of a coherent and sustained funding structure on which the future social and individual empowerment will be based. It is therefore necessary to support the members of the family and provide adequate psychological and material interventions when a child with disability is born. As a parent explains: "In my opinion, it is at this stage that services should intervene, it is here that a change should be triggered" (Biggeri and Bellanca, 2011b).[2]

The life project is thus the expression of the person's ability to reflect on his/her values, available options and aspirations. The aim of elaborating a life project through peer counselling is of starting a process of individual empowerment able to reveal adaptive preferences or negative adaptation to the circumstances faced by the person with disability. Therefore, the objective is not of appreciating the available options but of identifying potential opportunities, new goals and to work towards these. Empowering persons with disabilities is not about making them include certain activities in their life project; it is about increasing their capacity to form self-determined preferences. Therefore, during the reflective process that leads to the life project, comprehensive knowledge regarding good practices and other relevant information is an essential requirement.

Fig. 1 represents the dynamics of the process of strengthening individual capabilities and of the initial level of agency achieved by moving towards the space where E-capabilities, team agency, motivations and social empowerment processes are activated with the help of some suitable tools (peer counselling, self-help groups, human rights enforcement and information flows).

From a theoretical point of view, peer counselling represents a specific E-capability, since it implies a condition of human proximity and a range of experience-based and professional competencies, which enable to work on the person's agency, motivations and rights. The advantage of such an E-capability is connected with the fact that it is bound neither to parental nor to professional "neutral" relations. In fact, despite carrying out a very relevant, sometime irreplaceable function, in some circumstances,

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[2] This assistance should be provided already in the hospitals, where, unfortunately, several episodes of segregation and abandonment of the new parents took place. In the UK, a programme called "Post-Birth Care for Mothers" is present in hospitals.
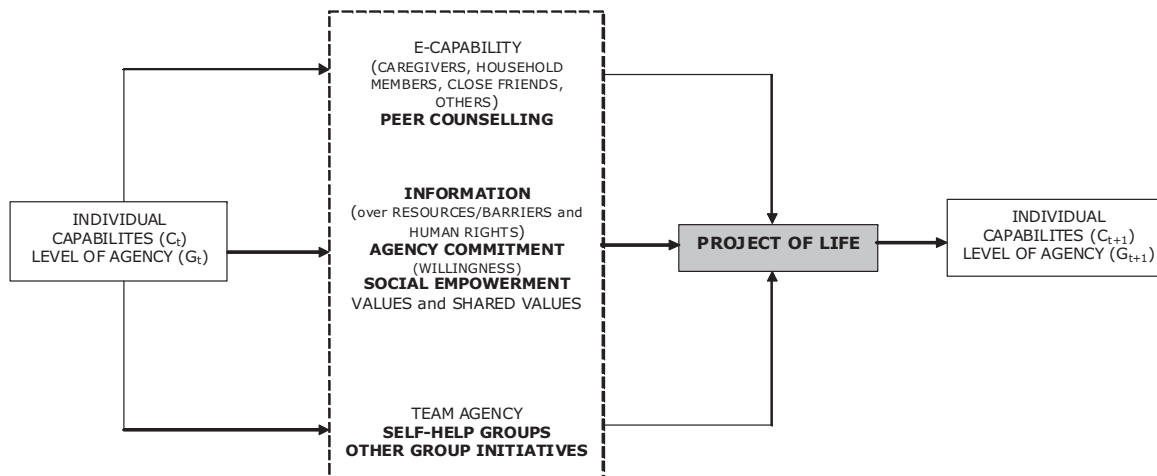
**Fig. 1.** The life project as an instrument and the instruments for the life project.

Our elaborations on Biggeri et al. (2010).

these relations may have a negative impact on the person with disability's self-determination and agency (and sometimes also on the caregiver's capabilities).

Such an E-capability might play a relevant role also for the parents of children with disabilities. Indeed, some parents do not manage to overcome the situation they enter as soon as they learn about their child's impairment diagnosis. As highlighted by some parents, in order to face this challenge it is necessary to develop a new attitude. "All of us, can do something and we must not lay down on the handicap; on the contrary, we must make the most of residual talents, which are always present" (Gucci, 2009, p. 100), and to acknowledge that external support is needed: "The truth is that I was not ready. I was persuaded that we did not need an external support, that we could do everything on our own" (Gucci, 2009, p. 61).

## The Life project, peer counselling and self-help groups

> "che ntender no la può chi non la prova"
> Dante Alighieri (The New Life, Chapter XXVI, 1295)[3]

### Life project

The life of individuals with disabilities is characterised by constant violations of human rights (Light, 2000) that are most often not recognised (Quinn and Degener, 2002). It is sufficient to read the biography of person with disabilities (Coppedé, 2004) or look through the Disability Studies in order to see how the society incapacitates (Oliver, 1996) those with functional diversities (Palacios and Romanach, 2006). This leads to a limitation in access to goods, services and rights, representing a process of personal and social impoverishment which, compounded with barriers, obstacles and discriminations that the person faces, adds a substantial reduction in competencies and capacities. This process affects all types of functional impairments and is different for each individual, as it is a result of the combination of personal, social and environmental conditions.

Hence, often individuals with disabilities have to limit their life project, as they experience constant obstacles and socio-environmental barriers, that they sometimes view as an inevitable consequence of their psychophysical condition. Indeed, individual impoverishment processes affect not only the "doing" but also, and recurrently, the perception in the possibility of "doing", thus creating psychological frustration and the feeling of dependence and hopelessness. The close relations between capabilities and will, body and mind, desires and potentialities, may lead to various levels of mental distress and psychological problems, which no service is equipped to deal with. Therefore, impoverishment processes stay hidden and are rarely made explicit, as they are often perceived as direct consequences of the person's psychophysical condition. Individuals with disabilities internalise this negative vision, further denying themselves opportunities, rights, desires and dreams (Dryden, 1999; Bateson, 1997).

According to Barbuto et al. (2007), the life project is the tool par excellence to trigger an empowerment process, and strengthen agency. Firstly, this is linked to the fact that the aim is to elaborate a project (and not a plan pre-defined by technicians) where the beneficiary is the main decisions-maker and actor, supported by other persons, professionals or not, throughout the empowerment process. Indeed the project's cornerstone is the individual who determines an adequate path towards the enhancing of capabilities and acquisition of competencies, on the basis of his/her requirements and socio-individual objectives. In this sense, the individual project is a progressive acquirement of autonomy, self-determination, independence and social inclusion. The elaboration of the project is a process that requires access to adequate and relevant advice and a multidisciplinary approach based on some key elements: taking into account the history of the individual (observation stage), giving

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[3] As in the quote of Dante Alighieri, at the beginning of this section, there are periods of our life when emotions and feelings overcome us. In these situations it can be difficult to communicate especially if emotions and feelings are perceived as negative. We are not able to communicate because we think that the other persons are not able to understand and share our feelings. Therefore, only persons who lived similar deep events can understand and share. "What is essential is invisible to the eye, the little prince repeated", Antoine de Saint-Exupéry, (The Little Prince, Chapter XXI).

specific attention to ways and means of reaching the goals that have been set; analysing past and present documents and recording these in the system; examining the abilities A-capabilities, opportunities O-capabilities and potentialities P-capabilities; evaluating the degree of autonomy and the possibility of taking advantage of secured rights (evaluate and combat discrimination and the lack of equal opportunities); identifying useful assistance; establishing a list of positive actions and solutions that enhance self-esteem, self-determination, competences, acquirement of abilities, development of social and interpersonal relations, enjoyment of rights; setting-up of a detailed timetable for provision of services and interventions.

Therefore, the observatory stage of the life project needs to be followed by a creative stage and by a critic-realistic one (which allows an in-depth assessment of the "degree of realism" or the plausibility), and finally leads to the implementation stage (Barbuto et al., 2007, p. 132). In the latter phase, an operative and practical outlook is needed (synthesis, discussion, concentration, attention to detail, and search for information) with the aim of re-discovering and generating vitality, where personal capacities are directed in order to accomplish concrete actions. The action is where effective changes operate (Barbuto et al., 2007, p. 133).

As already underlined by Barbuto and others, defining a life project means taking a comprehensive view of all aspects of life. Indeed, this exercise implies:

> "devising clear objectives in the management of one's own life, together with a level of maturity and responsibility, given the fact that any choice is not exempt from risks and criticism, especially due to the fact that tools and personal assistance services, are not sufficiently or at all adequate to the identified needs"
> (Barbuto et al., 2007, p. 58).

In the Italian legislation the life project corresponds to the individual project envisaged in art. 14 of bill n.328/2000, which however, should be better specified in the health and social system, and which obliges a single public officer to define a cross-sectional project. Nevertheless the on-going need to update the type of the services, which would offer real support towards the empowerment of the individuals, persists (adaptation of peer counselling, participation in groups of mutual aid, centres and services for an independent life).

Another central element of public policies within this field is the prevention of disabilities. Going beyond the approach that conceives disability prevention solely as a medical field, the CRPD has assigned major responsibilities to States in order to address the prevention of disability from the social aspect, removing obstacles and barriers, fighting unfair treatment and discrimination. Unfortunately the awareness of decision-makers is often far removed from viewing disability concerns according to the social model, based on the respect of human rights and the CA. This is reflected in the fact that Italian legislation on disability incorporates contradictory laws, based on old models of disability (for example the law n.118/71, 104/92 and 18/2009).

The research conducted in the Tuscany Region highlights a strong and widespread interest of various stakeholders for the life project (Biggeri and Bellanca, 2011b). Using the words of a person with disabilities: "It is very important for an individual with disabilities to pre-fix objectives in order to avoid cognitive weakening on his/her state" (Biggeri et al., 2010). Within the focus group discussions, the life project was recognised as a tool for promoting change in regional policies for disability, since it gives the person with disability an active role, and considers him/her as the central agent for the definition of his/her life objectives. For the members of the focus group, the main objective to pursue was the access to autonomy and the development of agency, namely the freedom for self-determination. This is a complex process, since it requires a continuous interaction between the person and the social cultural and economic environment. The life project preserves its value in the case of persons with intellectual disabilities (Bonfanti and Biggeri, 2010).[4]

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[4] Bonfanti and Biggeri (2010) analysed a successful practical experience of life project for 90 adults with severe brain injury. This experimental project is conducted from February 2009 by Dr Roberta Chiaramonti (the case manager, neurologist) at the Day Service of the S. Giovanni di Dio Hospital (public) in Florence thanks to the collaboration between the Hospital Unit and the association ASSCA (a regional NGO formed by parents and caregivers of persons with severe brain injury) (Bonfanti and Biggeri, 2010; Osservatorio qualità ed equità, 2010; Tosi et al., 2010).

The interviews with parents and teachers and social workers working with children and teenagers show how essential the life project is, especially for these age groups (Biggeri and Bellanca, 2011a). In the Italian education system (up to the minimum compulsory education level), families of children with disabilities are included in a "compulsory" assistance programme that addresses disability-related issues through a host of standardised services. For a decade, the Italian education system has used the Individual Educational Plan (Piano Educativo Individualizzato [PEI]), elaborated by a functional micro-team (childhood neuro-psychiatrist, social worker and educators). This document contains the description of well-balanced and integrated interventions, prepared for a certain period of time for pupils with an impairment.[5] When it is well elaborated and actively includes the parents of the child, the PEI might have similarities with the life project.[6] However, it differs from the latter on one fundamental aspect: it is strongly focused on school-based learning, omitting physical, social and autonomy aspects. Moreover, it is restricted to children who go to school. It has been underlined by participants to the interviews how at the end of school, when the teenager with disability becomes an adult, the family is suddenly devoid of any coherent plan for the further development of their son/daughter.

It is therefore necessary, beginning from school age, not to focus solely on academic learning but to work towards developing the autonomy necessary not only for the present stage but in future as well. It is important to identify other spaces, apart from school, where the capabilities and the opportunities of the child can develop and expand, and to facilitate the detachment from the symbiotic link with parents. In theory, the agreement between the Italian State and Regions (20/3/2008) for children with disability at school focuses on a new space of continuity among the school and the area to be enriched to take into account the child in a holistic manner through a life project.

We would like to conclude this section by cautioning that even if the life project is a tool, which may allow individuals to set and achieve important goals and modify attitudes towards persons with disability and their caregivers, it must not be considered as an acquired panacea. During a focus group discussion (Biggeri and Bellanca, 2011b), it was emphasised that taking decisions pertaining to the life project, through the creation of sub-objectives and actions, is not easy. Often tools and assistance services, such as public transport, are completely lacking or not sufficient in order to meet the needs of persons. However, it is essential to claim through individual and collective actions the right for better public services.

### Peer counselling and peer support

Living in freedom, in accordance with personal preferences and choices, represents a complex path for individual with disabilities, and implies overcoming several obstacles. Individual experiences are closely connected to the socio-cultural context, more often than not tainted with rejection and prejudice. Discrimination is omnipresent in social and interpersonal communication and hinders the lives and interaction of persons with disabilities by creating a negative super-structure around the authentic core of the individual, and severely impeding his/her possibility of expression and development. At the end of the 1970s, a group of students with disabilities at the Berkeley University, used previous experiences in other highly marginalized groups (Afro-Americans, women, etc.) and decided to meet regularly and offer each other "time" to communicate personal experiences, share and elaborate on individual and collective strategies, in order to cope with problems related with their disabilities (Silverman, 1993).

Peer counselling is a specific form of counselling that draws upon experiences of associations and individuals with disabilities. It favours personal empowerment and consequently, encourages social emancipation, allowing the expression of personal needs, aspirations and potentials. All remaining obstacles, that could be defined as ordinary, engendered by physical barriers, absence or inadequacy of

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[5] The objective of PEI is to implement the right to education and schooling, as mentioned in the first four paragraphs of art. 12, law n. 104 del 1992. The PEI is an inter-institutional operational project that links professionals in schools, and social and health services, in cooperation with the families. It is a personalised educational and didactic project related to the learning dimension and linked to rehabilitation and social aspects.

[6] In June 2010, Switzerland has presented a bill planning a life project for all children during compulsory education.

services, lack of adequate measures, can be convincingly opposed if the afore mentioned fundamental elements are addressed. One can consider peer counselling as a psychosocial intervention that can trigger an empowerment process, not only at an individual therapeutic level, but also in a social and political sense.

The peer counselling experience is, as in any human relation, characterised by its own uniqueness and singularity (Giusti, 1995). It assumes that the person who decides to embark on this path has a strong motivation for change. It is a long and strenuous process, since it is embedded in the residual competencies and ability of the person to grow, despite the considerable problems he/she faces: "Each individual has the duty to find the right answer to his/her own condition" (Barbuto et al., 2007, p. 78).

This support relation can be implemented both individually and in groups. This flexibility allows the person with disability to move forward in the problematic areas of his/her life. ". . .If, on one hand, face to face peer counselling, can reassure vulnerable individuals, who may not be adequately equipped to sustain emotional discomfort and general feedbacks from a group, on the other, moving to group counselling allows for empowerment and broadening of interpersonal abilities and can be a means of fighting experiences of guilt and shame. Both forms of counselling are characterised by a two-way process, in which one side activates individual resources of the other side, in accordance with the problems and personal objectives" (Barbuto et al., 2007, p. 49).

Two elements are inherent to the counselling process. The first is the relationship of trust with the counsellor. The individual with disability who is pursuing a personal empowerment path and has achieved an independent life along with a profession, represents the living evidence of the possibility to reach objectives: "If it is possible for him, it will be possible also for me" (Barbuto et al., 2007, p. 49). The second element is the collective energy – in the case of group counselling – in which sharing of various achievements creates an "echo effect", which facilitates feedback and awareness.

In peer counselling, the analogue experience of the counsellor and the consulted creates an experience of sharing. This is a fundamental element since it triggers a spontaneous phenomenon of self-reflection, creating a first step towards identification, which represents a major incentive to embark on an in-depth and on-going counselling. In this context, the more the disabilities of the two actors are similar – concerning the severity level and type – the more intense the relation and the reciprocity level will be, facilitating trust and identification.

Del Corno and Lang (1996) argue that the counsellor needs to be trained through a process in order to allow him/her to understand and master relational and psychological aspects linked to the conditions resulting from the functional problems – should always bear in mind that the meeting space and time belongs to the subject of the counselling. In this sense, peer counselling embraces the Rogersian principle (Rogers, 1970, 1975; Patterson, 1990) of the "client-centred therapy" (Barbuto et al., 2007, p. 50). The peer counsellor provides support when requested by the individual with disability, in different contexts.[7] In Europe, these professionals cooperate within and outside public, educational, occupational and social services.

According to Barbuto et al. (2007), during the process there is often initial difficulty due to the internalisation of limitations, although acquiring and accepting this, is the first step towards reducing this resistance. ". . .These fears and feelings of helplessness are transformed into self-esteem and ability to face challenges. In other words, I have started this inner growing path without realising it, and I have started to love myself from the outside, in order to appreciate what is inside" (Barbuto et al., 2007, p. 83). Furthermore, the peer counsellor should not show any inclinations towards providing the answers, but act as a facilitator in the self-determination and awareness process. The disability condition, once stabilised, does not require specialists but a facilitator for the process of acquiring full citizenship. This can be achieved by strengthening personal resources (psychical, emotional, relational, etc.) and through securing external aid that the person has at his/her disposal (laws, technology, etc.).

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[7] For example in 1998, DPI Italia, in order to identify persons with a disability able to perform this professional role, decided to promote a pilot project, called "Peer counselling; a method to design an independent life" that lasted two years (January 1998–December 1999). After this first stage, the Province of Catanzaro financed some further training to the same students. Since 2002, the University of Calabria (UNICAL) provided a Disability Service (from the Law n. 17 (28 January 1999, Integration and modification of the general policy law n. 104, 5th February 1992), i.e. activity of peer counselling for students with disabilities, managed by trained and certified persons.

It is necessary to state that the peer counselling (based on the individual) impacts the individual subjective level and is also closely connected with the social dimension, in order to build equal opportunities and ensure the enforcement of rights. Therefore, this method needs a lot of information and support. This could be endorsed by a disability observatory at regional level (see Biggeri et al., this issue) that strives to give substance to individual plans that lead to independent lives. In other words, the peer counsellor should be able to provide advice regarding the use of the legislation concerning disability and have adequate knowledge of the services and resources provided by local authorities. But he/she must also demonstrate competencies related to the needs of disabled citizens issues and if and how these are being addressed within institutions and public and private bodies.

Peer support (recognised in Art. 26 of the UN Convention) is a service that could provide information facilities and deals with specific problems related to target groups living in socially disadvantaged conditions. Its actions are devoted to promoting the culture of diversity and favouring policies directed towards non-discrimination, equal opportunities and social inclusion. It makes the network of organisations of people with disabilities and their families more effective, encouraging empowerment and active participation at all levels of the society, so that each one can become more aware of his/her human and civil rights and claim their enforcement.

In this perspective peer counselling emerged in the research as a useful tool which, by favouring the acquisition of awareness, allows the self-realization of the individual (Barbuto et al., 2007). This emerged also in the study for the Tuscany Region. For instance, one person with disabilities pointed out: "I believe this is a good strategy, which has given good results in other areas [...]. I also believe that while working with individuals with disabilities, there is a need to take into account that they need to relate with others who have faced similar problems. In the case of teenagers with disability, I believe that, this is needed for them, in order to get to know themselves and to build their own personality. (...) Later on the relation with others also becomes important (...); the connections are often immediate, and generally the same language is spoken" (Biggeri et al., 2010). Furthermore, the participants in the focus group discussion agreed that peer counselling should be provided to parents of children with disabilities, and also to the individual whenever possible. "The person should be the main character of his/her own life, and therefore, he/she must identify the assistance and services that are required" (Biggeri et al., 2010).

Several interviewees expressed doubts and concerns with regards to the counselling abilities of individuals with disability and their caregivers, based on two required elements: specific professional competencies and aptitude and they stressed the necessity to receive training and to include the peer counsellor as an officially registered professional.[8] This will in time enable a precise definition of the duties of the counsellor on the same level as those of other professionals (doctors, social workers, psychologists) that support persons with disabilities cooperating and collaborating with other competencies. In a number of complex cases a case manager can facilitate the interactions and teamwork of different operators and experts.

*Self-help groups*

Each of us faces critical situations that become more dire and frequent for individuals with disabilities, due to a discriminatory culture, as well as each personal and collective history. Persons with disabilities live lives in which relationships, the possibility to share experiences and care are often strongly hindered. As a result, they experience isolation and can most often count only on themselves or on their immediate family. Self-help groups allow them to acquire the consciousness that others might have lived through similar psychological and material difficulties, for instance at the point of diagnosis and in accessing information about medical treatments and rehabilitation. They also give the possibility to share help to review problems and difficulties and to consider future choices and decisions with more inner peace. The exchange that takes place within self-help groups allows an individual to expand the capacity of gaining control over his/her own situation. "Already from the first

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[8] The Italian university law has introduced peer counselling (DPCM 9/4/2001 – art. 4 della legge 2/12/1991, n. 390 – art. 14 comma 10). Unfortunately this figure has been interpreted differently by the Italian universities and some time misinterpreted.

meeting, the new member realises that this could be the right place to solve his problem. He realises that those unknown persons, although apparently normal, have something special and welcome him as if they have always known him. They open their hearts with their stories and catharsis, revealing things that they would not confide to their best friends or to their family. Thus, the new comer observes them, listens to them and through their relaxed faces and calm words, feels, in a tangible way, that there is a real way to escape" (Giampaolo Angius).[9]

The self-help group, based on a social intervention, can be an effective and adequate answer in order to trigger an empowerment process for persons with disabilities and their caregivers. The need for self-help groups in the disability field is also due to the inadequacy and lack of answers provided by social and health systems, policies and legislation. By promoting mutual support between persons, self-help groups break isolation and create a space for sharing experiences in an informal, genuine and constructive manner. Indeed, Ibrahim (2009) underlines how self-help can be a catalyst for human agency and collective capabilities.

A fundamental remark in order to understand the value of self-help in the field of disability is, without any doubt, the importance of empathy between the members of the group: "We are on the same boat" as stated by Liss (1996, 1998). The members of the group share common experiences, similar problems and, contemporaneously, put into action similar or even different strategies. Indeed, the characteristic and novelty of these groups is that the subject is both supplier and consumer of this support. This often allows the individual to cease being a passive recipient or subject and thus, move beyond feelings of uselessness and self-mistrust.

In the majority of professional interventions, the interpretation of the problem and its solution take place at the individual level, or according to the family point of view, whereas in the self-help groups this process takes place in a participatory and collective manner. The self-help, being among peers, does not allow personal responsibility delegation onto other members. In this sense the subject that participates in a self-help group acquires competencies for better management of his/her own suffering and moves away from the tendency of viewing his/her well-being as being dependant on various professionals (Tognetti Bordogna, 2002).

When considering a self-help group, various steps should be followed: the welcome, hearing the story in an environment of mutual acceptance; sharing strengths and determining things to "do" together, claiming rights and protection; being able to choose to go further, to do other things; having the chance not to withdraw into a state that becomes totalising, absolute and without ways for escape.

According to a research conducted in Italy by Focardi et al. (2008), the self-help group is in general small in size and is normally formed by volunteers, in order to offer help and paths towards autonomy for those facing difficulties, in order to promote personal and/or social changes. The main characteristics of such groups that emerged in the research in Italy (Barbuto et al., 2007 and Focardi et al., 2008) are:

- the establishment of an equal relationship amongst all members;
- the freedom to identify one's own difficulties, in order to generate communication based on an exchange of experiences;
- this communication consists of mutual exchange of information, emotions and stories;
- the sharing of common objectives: all members have some common aim;
- the inclination to take action. The facilitator can encourage this exchange and participation, without modifying the vision.

Self-help groups and the civil society associations that promote them, cope with complex issues and challenge institutions (municipalities, districts) and social and health services (health companies, rehabilitation facilities, hospitals). As stressed by Focardi et al. (2008) however, the majority of these experiences express the need to re-enforce a network of relationships with the institutions, thus addressing social and health questions by going beyond the simple considerations pertaining to the immediate well being of the participants. The way in which this cooperation takes place is

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[9] http://www.poesieracconti.it/racconti/opera-3556.

still inadequately structured and rarely formalised. For an effective grassroots-level action there is an urgent need for coordination and for a minimum level of institutionalisation and approval from local governments.

Recently the WHO, in cooperation with Associazione Italiana Amici di Raoul Follereau (AIFO, an Italian NGO), has promoted a project in ten regions around the world in order to compare the achievements of various self-help groups in terms of effectiveness of the traditional medical treatments and rehabilitation techniques (Deepak, 2007). In fact, it has been noted that once the medical treatments and rehabilitation techniques have stabilised the functional problems (called chronic disease in international medical terminology), self-help groups become more effective and appropriate (and also more cost effective on an economic level). Taking into account that in the future, medical care for chronic functional problems will represent 70% of global health expenses (Deepak, 2007), the use of self-help groups represents an essential element to promote capabilities and enhance abilities of individuals with disabilities, possibly within rehabilitation projects and at the community level.

## Conclusions

Any policy reform which claims to improve the well being of persons with disabilities effectively and efficiently, has to focus on their potential and opportunities. Such policies would help to expand capacities and ensure enjoyment of rights and, at the same time, reduce the costs of services, which are not required by persons with disabilities. Such a reform needs to enhance and sustain individuals, most often the family members that face the challenges on a daily basis in order to meet the psychophysical needs and have an impact on the capabilities of the persons with disabilities.

The pivotal instrument for change is the opportunity to elaborate a personal life project which, alongside a more traditional technical assessment which accompanies the person with disability in the Italian system, provides the prospect of focussing on a bigger picture of the situation of every individual, which takes into account his/her needs and aspiration. The drafting of the project enables the person with disability to set some realistic goals and his priorities, which can be modified over time as and when needed. This life project can/must be used to decide which strategies one should follow, and identify the services, public or private, a person needs. If we compare the paucity of information that can be drawn from a mere assessment of functional limitations or on the narrow conclusions based on a medical diagnosis, with the multi-dimensionality and comprehensive view of a tailored life project, it is easy to understand to what extent public policies and related services could be re-defined and enriched.

It is evident that over time, some objectives may change, along with the circumstances, the physical changes, the needs and means of communication. The project is therefore not a static object but a tool, which evolves through the actions of adaptation and exaptation, which are both part of the process. Many people, through these processes, have learnt to accept and live with their disability (Barbuto et al., 2007; Bonfanti and Biggeri, 2010). These persons enrich the lives of those they live with, by showing a new perspective on which to start building societies based on inclusion, acceptance and respect of diversity (Barbuto et al., 2007, p. 35).

Peer counselling and self-help groups can be fundamental instruments of this process. The peer counsellor is a complementary role that cannot be substitutive of those already present in the system. Our findings show that stakeholders clearly believe that competencies, professionalism and coordination of efforts can play a fundamental role in improving the well being of persons with disabilities and their families. Since often these are not present in the area they should be duly trained and coordinated.

Elaborating a life project in order to expand autonomy is an exercise that requires the support of different people with diverse professional backgrounds, civil society association participation (such as disabled people's organisations, and above all institutional support and a coordinated and legitimate system at the local/regional level (see disability observatory Biggeri et al., this issue).

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