



The Social and Cultural Integration of Disabled People: Approach and Practices of Social Participation

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«To live with, does not mean to do good with generosity, but to recognize that Eric is a human being full of desires; it means establishing with him a bond of trust and mutual understanding. Walls begin to fall, fears to vanish (...). For me, being open to an encounter is the most human thing there is, it should be part of any relationship»

(J. Vanier 2011)[2]

Introduction

Disability is a global phenomenon. The first *World Report on Disability* (2011) issued by the World Health Organization and the World Bank has estimated that more than one billion people, namely 15% of the world population, are affected by some form of disability. Some have called it the “world’s third nation” (Schianchi 2009). Moreover, the social borders of this “nation” are extended even further: disability pervades the everyday life of families and social institutions such as schools, workplaces, cultural and recreational associations, health and social services.

Disability is also a growing phenomenon. In the 70s only 10% of the world population was affected by some form of disability. The number of disabled people will most certainly continue to grow in the future due to an aging population and the higher impact of disabling chronic diseases. The growth will become even more serious in specific areas at risk because of additional health, social, and cultural factors. Environmental pollution, unhealthy lifestyles, work-related injuries, wars and violence – all these phenomena can have disabling effects (WHO and World Bank 2011).

The abovementioned dynamics remind us that a person can become affected by some form of disability at any point in time, especially under the pressure of the aging process. Consequently, a new conception of disability has arisen according to which disability is a universal phenomenon intrinsic to the human condition (Bickenbach *et al.* 1999) and a powerful sign of our vulnerability (Kristeva and Vanier 2011).

Martha Nussbaum has pointed out that with the increase of life expectancy “...the independence we enjoy ends up being a temporary condition, a stage of our life in which we gradually enter but that we also begin to leave too quickly” (Nussbaum 2001, 795). Similarly, Alasdair MacIntyre envisions a form of political society where “our interest in how the needs of the disabled are adequately voiced and met is not a special interest, the interest of one particular group rather than others, but rather the interest of the whole political society, an interest that is integral to their conception of their common good” (MacIntyre 1999, 130).

MacIntyre’s treatment of the needs of disabled people, as one fundamental element of the good of the entire political community, implies a certain view of the common good. In this view, both the holistic and individualistic conceptions of the common good have proved to be inadequate. As Donati states, “today’s society (...) expresses the need of new common goods (...): common in the sense that only communities of people, only primary groups and associations can express and protect those needs. This is a new generation of rights; precisely the generation of the *human* rights, beyond civil and political rights and those of socio-economic welfare” (Donati and Solci 2011, 213. Italics in the text).

The 2006 United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) is aware of this need and preludes a deep change of the policies relative to disability. Countries which subscribe to CRPD are committed to promote, protect, and guarantee the full and equal enjoyment of the fundamental rights and freedom to all disabled people. Among the inspiring principles of CRPD we find the following (art. 3): the respect for the inherent dignity, individual autonomy, including the freedom to make one’s own choices, and independence of persons; non-discrimination; respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; full and effective participation and inclusion in society.

Such principles can become effective only if they translate into policies, services, and practices. What are the policies and practices capable of fostering a participatory society in which disabled people can “flourish”? According to what criteria can they be considered “good”?

The aim of the present paper is to explore the hypothesis that we should consider “good” only those policies and practices that treat the social participation of disabled people as a “relational good”. Relational goods, as Donati explains, are “those immaterial entities (intangible goods) the consist of social relations that emerge from subjects’ reflexivity that is oriented toward producing and enjoying together, in a shared manner, a good that they could not obtain otherwise” (Donati and Archer 2015, 213. *Italics in the text*).

I will proceed as follows. First of all, I will consider the cultural exclusion to which people with disabilities are often subject, especially the devaluation of their social identities. Secondly, I will present the two most influential conceptions of disability used today in developing inclusive policies, namely, the medical model and the social model, and I will point out that they do not take the *agency* of the person with disability sufficiently into account. Thirdly, I will focus on principles of social participation elaborated by the *Independent Living Movement* (one of the most influential organizations of activists with disabilities), and adopted by CRPD, where the agency of disabled people plays a fundamental role. In this part of my paper I will dwell on three different approaches to social participation and consider whether they have the resources to promote practices which center on relational goods.

1. Disability and cultural exclusion

The available empirical evidence primarily concerns the condition of disabled people living in developed countries. We know relatively little about the 80% of the world population living in developing countries.[3] The *World Report on Disability* (WHO and World Bank 2011) sketches a picture in which the condition of disabled people presents many disadvantages compared to that of people without disabilities, including health, educational, work, and financial disadvantages.

It is necessary to implement new inclusive policies in order to counterbalance this situation. The World Bank has recently defined social inclusion as “the process of improving the ability, opportunity, and dignity of people, *disadvantaged on the basis of their identity*, to take part in society” (World Bank 2013, 4. *Italics added*). The analysis of the phenomena of exclusion is often limited to point out that some social groups are at times underrepresented, but what we need is a more rigorous reflection on why this happens and on all the processes generating social exclusion, not only those related to a situation of deprivation. In other words, we have to go deeper into the systems of beliefs and social norms that feed the processes of exclusion.

This perspective is especially relevant for disabled people. Their disadvantage does not simply consist in having less easy access to social and financial resources, for their situation is weakened by all the symbols cultures use in order to cope with “uncanny” phenomena such as disability (Korff-Sausse 2009, Barnes and Mercer 2001, Ingstadt and Whyte 1997).

Disabled people are treated in different ways depending on how their disability is perceived with respect to the socially accepted criteria defining what a full personality is. Western culture has produced certain stereotypes of disability.[4] Categorizing a subject based on stereotypes allows another subject to reaffirm his own self-image when this is threatened (Fein and Spenser, 2000). Some think that the impaired body represents a metaphorical “crutch” for *ableism* (Goodley 2011), namely, “a network of beliefs, process and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human” (Campbell 2009, 5). Disability would provide then some kind of support for an ontology of perfection, which Western culture usually identifies with the independency typical of adulthood, with the capacity for physical and social autonomy (Priestley 2003).

The devaluation of the identity of disabled people is a constant in the history of Western society (Schianchi 2012, Fioranelli 2010, Stiker 1999). This has produced various forms of social exclusion: physical elimination, abandonment, segregation and discrimination (Ravaud and Stiker 2000). Contemporary societies are not fully immune to these risks. The physical elimination of people with disabilities in Nazi Germany paved the way to the Holocaust (Ricciardi von Platen 2011, Tregenza 2006, Burleight 2002). Although it takes a different shape, the shadow of exclusion is also present today. Some openly theorize the physical elimination of unborn babies with congenital malformations (Singer 2011). Besides, techno-normative devices regulate the routine of prenatal diagnostics in many countries (Ho 2008, Rapp 1999). In Europe, a significant number of pregnancies are interrupted when prenatal diagnostics show a malformation in the unborn baby (Volpi 2016, Euro-Peristat *et al.* 2013).[5] A similar approach to prenatal tests and pregnancy interruption is emerging in Muslim countries where abortion is illegal (Bryant *et al.* 2011). Abandonment is still widespread in Israel, where research has revealed that about 50% of babies with malformations are abandoned in the hospital by their parents. This grows to 68.4% in case of visible malformations (Weiss 2007).

A participatory society is a society in which opportunities and resources are more fairly distributed, also through more adequate “policies of recognition” of people with disabilities (Danemark and Gellerstedt 2004).

2. Conceptions of disability, identity and inclusive policies

The emergence of a different conception of disability, namely, the so-called “social model”, alternative to the “medical model”, has redefined the identity of people with disabilities and has motivated a development of new inclusive policies (Ferrucci 2004). While the notion of social disadvantage is common to both models, their respective account of that notion is completely different.

2.1 The Medical Model

According to the medical model, social disadvantage is a *consequence* of the disability. It is a deviation from the normal functioning of the organism that prevents the individual from those activities that make social integration possible. The causes of the disadvantage are thus identified with biomedical factors at the individual level.

When adopting this perspective, disability policies focus mainly on social and health services. Disabled people are subject to “therapeutic-rehabilitational” treatments in order to restore the biopsychic functioning of their organism, usually through the use of technology. The goal of the intervention is always to remove or reduce the deviation from biomedical norms, so that people can become capable of those performances that social roles require.

Participation in social life is then pursued through a process of normalization of people with disabilities that at the same time does not require any significant change at the cultural level. The social identity of disabled people remains neglected in its specificity because the focus of society is on removing those traits that are viewed as negative (Gray 2009).

2.2 The social model

The physical and social environment affects to various degrees the social disadvantage of people with disabilities (Allotay *et al.* 2003). The social model does not deny the biomedical components of disability; however, it rejects the idea that social disadvantage is caused by the psychophysical impairments as such. In their manifesto, the activists of the Union of Physically Impaired Against Segregation – the organization which has elaborated a social model for the first time – claim that disability “is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society” (UPIAS 1976, 3). The disadvantage results then from the inadequacy of social and economical structures, which *produce disabling effects* on people with structural and functional deficits and consequently exclude them from social life.

In order to restore equality, the social model goes in the opposite direction of the medical model. Instead of removing the disability, the social model aims to remove social barriers. Shakespeare observes that “underlying the idea of a barrier-free-world is an attempt to show that impairments can be irrelevant, and to make equal disabled and non-disabled people” (Shakespeare 2014, 42).

Within political discussions the social model has called attention to the sociocultural dimension of the disadvantage experienced by disabled people. By shifting attention from the body to the social and cultural relations involving the body, the social model has opened the path for the realization of new policies that go beyond health and social services. These include policies for the elimination of architectonic barriers, for integration in schools and workplaces, and for accessibility to the ICT.

While the medical model never takes the role of social structures into account, the social model relativizes the impairment by defining it as a “different but equal form of embodiment to not having an impairment” (*ibidem*, 42). However, the social model also has a distorted concept of social disadvantages because it neglects the *reality of the impairments*. In the same context, some limitations can be the cause of serious disadvantages, while others can be much less troublesome (Danemark and Gellerstedt 2004).

Either impairment or social structures are necessary but not sufficient conditions to produce disabling effects. What I want to suggest is that a disability becomes a social disadvantage only through the connection of the biopsychic limitations of the person with a certain sociocultural context. More precisely, I define it as “a social problematic relationship for the agent subject” (Ferrucci 2004).

Although they are contrary to one another, the medical and the social model have some elements in common. First, disability is for both a negative deviation from the social norms. Second, both take the social disadvantage to be a mere relation of “dis-adaptation” that does not recognize the intentionality of people with disabilities.

This idea of “dis-adaptation” is evident for instance in the integration policies in schools and workplaces adopted in Italy since the 90s. The law that promotes the employment of people with disabilities (legge 68/1999, *Norme*

per il diritto al lavoro dei disabili) has achieved commendable results. According to the most recent data, public job centers have played an important role, and thanks to them the disabled 10.1% of the population that has availed itself of the program has found employment (Ministry of Labor and Social Policy 2012). However, the procedures and functioning mechanisms do not adequately take into account the intentionality, expectations, aspirations, and all the other factors that characterize people with disability in their specific *agency* (Ferrucci 2014). The freely chosen occupation of which CRPD speaks is beyond reach of many disabled people, as is the freely accepted occupation most of the time.

Despite the criticism that the social model has received at the scientific level (see Grönvik 2007, Shakespeare 2014), the cultural breakthrough that it has produced has had a liberating impact on many disabled people. Firstly, this model has reshaped the image of the social identity of disabled people in such a way that they are no longer represented as victims of their bodies but of a discriminating society. Secondly, it has favored the emergence of a collective cross-impairment identity and the birth of organizations that do not act *for* disabled people, rather they are composed and lead *by* disabled activists (Barnes and Mercer 2011, Oliver 1990). By advocating for a different concept of social disadvantage, these movements have challenged the dominant representations of disabled people as passive subjects with no agency and have proposed a positive conception of the person with a disability.

Over the past years, these new forms of organization have produced both a “cultural” and “structural elaboration” (Archer 1995). The laws that have stemmed from them, such as the CRPD, delineate the new scenario for the implementation of disability policies.

3. Human rights and independent living: practices of social participation

The “full and effective participation and inclusion in society” of disabled people (art. 3) is one of the guiding principles of the CRPD, and we find it restated in several articles.[6] Despite the importance of human rights, as Carozza argued in his paper, international human rights systems have structural constraints that limit their capacity “to bring about dramatic social transformations in the direction of inclusive participatory societies”, because “the practice of human rights today tends too strongly towards extreme forms of individualism and finds relational goods very hard to account for” (Carozza 2017). From a sociological perspective, the questions are the following: how does the CRPD conceptualize participation? In what way does it translate into policies and practices? What are the outcomes?

The CRPD introduces a new concept of disability, for which “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (Preamble, letter e). This view adopts the biopsychosocial model of disability of OMS (2002) in the International Classification of Functioning, Disability and Health (ICF).

ICF identifies “participation” as the “involvement in a life situation” (OMS 2002, 19) but it does not pay much attention to intentionality. This is a major problem, since in the experience of disabled people intentionality is perceived as a very important factor (Morris 2009). Disabled people positively evaluate the possibility of choosing what activities they want to take part in (self-determination), participating in social contexts in which they feel recognized (social identity), going against the stereotypical concepts that portray them as dependent people, creating friendships (reciprocity), and putting themselves to the test to prove widespread social prejudices wrong. A further element that fosters social participation is the awareness other members of society have when it comes to the contributions people with disabilities make towards common wellbeing (psychological assurance) (Milner and Kelly 2008). Taking responsibility for one’s choices, feeling valued, being treated with respect, being recognized as people: all of these factors are crucial in promoting social participation (van de Ven *et al.* 2004).

A participatory society requires people with disabilities to be fully recognized as having agency, namely, as subjects capable of responsible and free decisions. This view of participation is crucial for the movements created and managed by disabled activists following the social model.

I will now focus on one of the most important and culturally influential organizations created by disabled people: the Independent Living Movement (hereafter ILM).[7] Its principle is pithily put in the formula “*Nothing about us without us*” and expresses a clear desire to participate in social life. The problem on which I would like to dwell now is how the principles of ILM translate into participatory practices. Adolf Ratzka, one of the leaders of ILM and founder of Independent Living Institute in Sweden, says that “Independent living does not mean that we want to do everything by ourselves and do not need anybody or that we desire to live isolated. Independent living means that we ask for the same choices and same control in our every-day lives that our non-disabled brothers and sisters, neighbors and friends take for granted” (Ratzka 2007, 2). This statement is particularly relevant for at least two reasons. Firstly, because it identifies independence with the possibility of choosing

the goals of one's activity. Secondly, because the idea of independence that Ratzka proposes presupposes a context of social relationships that makes it possible.

Various examples, inspired by the principles of independent living, have arisen in the past years. They have produced services and practices that follow three major approaches: the market oriented approach, the co-production approach, and the capabilities approach. The question is, then: do practices of empowerment of disabled people also generate social participation as relational goods? In order for this to happen, it is necessary that: 1) participants have a personal and social identity (there is no relational good among anonymous subjects); 2) the motivation for taking part in these social activities is not instrumental; 3) the conduct is inspired by the norm of reciprocity understood as symbolic exchange and not as mere *do ut des*; 4) there is full sharing among the participants, who produce and enjoy together the goods they have contributed to realize; 5) the interaction is not limited but rather built over time; 6) the participants tend to think in relational terms, namely, in light of the good of the relation (Donati and Solci 2011, 24-25).

3.1 The market-oriented approach

The organization of the Centers for Independent Living (hereafter CILs) are deeply informed by the sociocultural context of the US, centered on individual rights and deeply oriented toward the market. "It is time – wrote Ratzka – that disabled people too are recognized as full citizen with full freedom of choice not only on election day but also as customers in the market place" (Ratzka 2007, 9). Social participation is achieved through access to goods and services offered by the market. The more efficient the market of services for disabled people is, the more possibility they have to choose the most adequate services to satisfy their needs.

Such an approach to independent living excludes a priori the possibility that participation can be a relational good. However, it is instructive to see what happens in the case of the Personal Assistant (hereafter PA). As Shakespeare (2014) has pointed out, the PA model adopted by ILM reveals a limited conception of the relationships of assistance and support, which are more complex and heterogeneous. The relationship cannot be reduced to the mere execution of performances. We need to consider disabled people not only according to the framework of the ethics of rights, but also of the ethics of care (Kittay 2010).

In short, the market oriented approach and PA presuppose a well-developed agent subject, but they do not pave the way for a participatory society. The PA management practices satisfy only some of the necessary conditions to realize relational goods. They are not anonymous relations because they imply a certain degree of sharing. But involvement in relations is based on instrumental reasons and reciprocity is limited to the *do ut des*. These conditions, however, tend to grow over time: relations become less and less instrumental and they include forms of symbolic exchange. Despite the level of personalization that the service can achieve, the contractual structure hinders the development of a truly relational good.

3.2 The co-production approach

ILM also pursues its goals through practices of co-production, which synthetically "give citizen both more choice and more voice, as well as a more active role in provision of public service" (Pestoff 2015, 83).

Co-production is tightly linked to the rights declared by CRPD. Especially important are the right to be *actively involved* in the application of the law, CRPD policies, and all other decisional procedures (art. 4). Co-production practices also allow the disabled to have access to all the service production stages by exercising the right of decision and control, thus realizing the goal of ILM at its highest level. By assuming the role of "co-producers", disabled people take part in decisional processes for the production of those services that they might need at some point. What are the outcomes?

The European Platform for Rehabilitation (2016) has recently conducted a study on a sample of co-production practices. The results confirm that disabled people flourish when given the possibility of choice and control: this includes rejecting staff proposals that do not meet their needs, formulating judgments on services, and proposing ideas about what is important.

Among others, a meaningful experience of co-production is represented by KeyRing, a UK charity founded in 1990 to allow adults with learning disabilities to live in their own houses. Since 2006, membership has gradually extended to other client groups. Currently, it supports around 900 people in Living Support Networks in 54 separate local authority areas throughout England and Wales. Support is provided by local volunteers, by other members of the network who receive help, and by members of the local community. In general, the network is made up of nine people who live in their respective houses, not far from each other or from a volunteer who lives in the surrounding area, usually in a house provided by the association itself. The volunteer supports people in the network in various ways, including paying their bills, helping them find education programs, employment, and voluntary work. Moreover, it fosters their integration within the local community. The volunteer encourages

members of the network to sustain one another by sharing their respective competencies. When needed, the association can also provide the assistance of professional figures.

This experience had produced two very important results. First of all, it shows that disabled people can benefit from their coming together freely. In this way it has debunked earlier predominant “theories of normalization” which claimed that mutual help among people with disabilities produces stigmatizing effects. Moreover, it has been noted that among members of the network reciprocity spreads independently from the inputs of the volunteers, and that they develop a strong sense of belonging to KeyRing. Secondly, in contrast to other experiences in which help comes primarily from local communities, KeyRing stresses the contribution of the members of the network themselves (Poll 2006). This result of “enlarged reciprocity”, however, is not the result of an intentionally pursued strategy; it is rather a byproduct of the ordinary functioning of the network.

The approach to co-production has the potential to generate social participation as a relational good. KeyRing satisfies almost all the required conditions, although in different measures, both for what concerns personal and social identities and as an incentive for the members of the network to take care of one another. A crucial point, which puts reciprocity in motion within the network (but also beyond it) is the mobilization of the capacities of disabled people, offering their talents to other people to provide a service. In this way, social relationships so constituted become central and the involvement of the volunteer or professional figure becomes third parties. Most of the activities and performances imply a high degree of sharing. The *We-relation* is present and also expressed through symbolization, but is not explicitly addressed. The relationship does not constitute a relational social subject (Donati and Archer 2015).

Co-production was originally focused on the role of individual citizens, or groups, in the production of public services. But, as the case of KeyRing shows, the approach can extend to a third sector organization. In particular, KeyRing shows the impact that even small groups of people can have in fostering the active participation of people with different forms of disability (physical, mental, related to learning, autism), of the elderly, and of other socially-disadvantaged people.

3.3. The capability approach

KeyRing’s experience is characterized by the involvement of the local community, centered on co-production, understood as “provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users and/or other members of the community, where all parties make substantial resource contributions” (Boivard 2007, 847). A step in this direction is taken by Amartya Sen’s (1992) capability approach (CA) applied to the condition of disabled people (Terzi 2005, Mitra 2006, Trani and Bakhshi 2008, Dubois and Trani 2009).

Some Italian scholars have significantly developed CA with respect to disability, considered as a deprivation of capability (Bellanca *et al.* 2011; Barbuto, Biggeri and Griffo 2011). This has brought to some experimental applications of the capability paradigm (the most significant in Tuscany, see Biggeri *et al.* 2011) and to the operationalization of the same approach for programming disability policies (Trani *et al.* 2011).

CA and LM share the principles of choice and self-determination, and see the disabled people as capable of defining their needs, aspirations, and strategies. In CA “the agency of the individual is defined by values, beliefs and preferences within a given social environment that are consubstantial to the individual and not contextual factors” (Trani *et al.* 2011, 148). Moreover, CA endorses the “relational” concept of disability that is at the basis of CRPD, by considering both the particular condition of disabled people and the capabilities resources in the context.

In the CA approach applied to disability, the ascribed community capability is composed of collective, social and individual capabilities. Collective capabilities are the capabilities of given groups within the community (e.g. associations, self help groups, community-based organizations) and they benefit all the individuals of the community who participate in collective action, and not single individuals. Social capabilities are supplementary individual capabilities resulting from social interactions between individuals. They depend on the sharing of capabilities of one individual with others who will acquire similar capabilities as a result of the interaction.

The capabilities of people with disabilities depend on their personal conversion factors (e.g. disabilities, skill, gender, age), on social conversion factors (e.g. social norms, religious norms, disablism, etc.), and on environmental conversion factors (e.g. health services, mobility system, schools, social services, etc.) (Trani *et al.* 2011). According to Trani *et al.*, “they all contribute to the realization of aspirations by creating the conditions for exercise of freedom of choice of beings and doing of individuals and communities” (2011, 151). Conversion factors are material factors (e.g. infrastructures, income and services) or immaterial factors (e.g. individual abilities, social norms, identities, beliefs), which determine a reduction or an expansion of individual capability set. Conversion factors intervene at individual level, family level, community level and regional/national level.

At community level, some social tools, such as life projects, peer counseling, and self-help groups, can empower disabled people and promote their social participation (Barbuto *et al.* 2007, Barbuto *et al.* 2001).

The goal of the life project is to help disabled people define their objectives and aspirations by increasing their self-awareness. This requires a constant commitment to make decisions that concern them and to ask for the social help they might need. Peer counseling and self-help groups have a meaningful role in the elaboration of a life project. The life project is based on the assumption that the condition of people with disabilities is one of the possible manifestations of human diversity. For this reason, the project helps enable new capabilities that reflect the needs, values, and aspirations of the people involved, and not simply restoring preexisting conditions of normality (rehabilitation).

The life project is considered the fundamental instrument for the empowerment of people with disabilities because it improves their ability to define their preferences autonomously. The elaboration of the life project is a process in which many dimensions are intertwined (the person's history, objectives, means, different capacities to deploy – individual abilities, environmental opportunities, potentialities – degree of autonomy, etc.). The life project is thus a dynamic instrument that is modified over time according to the results of empowerment processes in which people with disabilities are actively involved.

Peer counseling is commonly used in the life project. It consists in a psychosocial intervention whose aim is to help participants elaborate their experiences, free themselves from their disadvantage, and obtain personal autonomy. The special relationship of peer counseling not only puts disabled people in a condition to be acknowledged as free and adult subjects, but also allows them to overcome the “phantom acceptance” (Goffman 1968) that they usually experience. The counselor offers a role model to the disabled people in order to achieve important results: greater awareness of their condition and challenges, greater freedom in personal and social deliberations, and an enhanced sense of responsibility.

Generally speaking, disabled people do not have extended networks of relations. Self-help groups put them in the condition to share their experiences with people beyond family members. Participants can express their problems, think about their future choices, receive suggestions and support, and obtain responses that personnel of public services are usually incapable of giving. These groups not only overcome social isolation, but also develop the agency of the subjects involved, with a resulting growth in autonomy. The constant shift in role – from service user to service provider – allows disabled people to go from a passive attitude to an active one. The difference between public services and self-help groups, therefore, is that while in the former case problems are tackled only from the point of view of the professionals, in the latter case solutions are the result of teamwork. In this way, disabled people develop useful knowledge to better manage their own condition and to become more independent from professionals.

CA practices (life project, peer counseling, self-help groups) have some of the necessary requirements for the realization of relational goods: the people involved have a definite personal and social identity, the motivations are not instrumental, relations – especially in self-help groups – are governed by the norm of reciprocity among the participants, and the good produced implies a significant degree of sharing. Nevertheless, in this case the CA framework does not take the relation into full consideration, but is rather content with focusing on the two poles: the individual with his or her capacities on the one hand, and the socio-environmental context on the other hand. Social relations become an object of attention only when individual limitations are so serious that they jeopardize agency (for instance, in the case of mental impairment). This is the only case in which the contribution provided by family members to the wellbeing of the person with a disability is adequately treated. CA fails to observe the emergence of social and community capabilities from the combination of several individual capabilities (Dubois and Trani 2009).

Concluding remarks

I began by recognizing that the devaluation of the identity of disabled people is an obstacle to their inclusion in society, no less than inequality in the availability of economic and social resources. This is due to the more or less explicit social stereotypes that prevent society from fully acknowledging the personhood of disabled people.

The emergence of new activist movements has contributed to a redefinition of social identity in positive terms. The policies resulting from the social model have significantly contributed to the removal of many barriers, which cause the social exclusion of disabled people from many dimensions of social life. Despite these contributions, the way in which these movements pursue the goal of inclusion relies too much on the resources of the system, and therefore continues to disregard the agency, the capacity of self-determination, and the autonomy of disabled people. These aspects are central in their social experience but haven't found adequate attention.

After the CRPD, disability policies entered a new phase because they became linked to the problem of the recognition of the human rights of disabled people. One crucial point is the right to full participation in social life, according to a principle of equality with everybody else. Involvement in a life context is not enough to guarantee social participation. According to the principles of independent living, involvement should occur as the result of an intentional choice, capable of expressing the self-determination of people with disabilities. Self-determination is the means through which realizing full social participation becomes possible. Independent living does not mean being alone, but rather choosing relational contexts capable of acknowledging and valuing the agency of people with disabilities. According to this perspective, social relations can have an “enabling” or, to use Sen’s terminology, “capacitating” effect.

This dynamic makes the realization of a relational good possible on the basis of the elements of disability themselves (functional limitations, intentionality of the subjects, social normativity, value orientations). As we have said, a relational good with respect to disability is a good that can be realized only through the active participation of disabled people, in such a way that they can realize the fundamental human good of sociability.

The market approach, the co-production approach, and the capability approach consider the principles of independent living in different ways, but not all of them satisfy the necessary requirements for the emergence of participation as a relational good. The market approach is certainly unable to do so. Co-production and CA satisfy the highest number of requisites for the realization of the relational good. Co-production as implemented by KeyRing is especially capable of generating networks of extended reciprocity. Nevertheless, even these two approaches have not yet developed complete relational reflexivity, where the relation between people with disabilities and without disabilities becomes a constitutive element of the identity of the participants (Donati and Archer 2015, Donati 2013).

The road to a participatory society for disabled people will be the one in which, as MacIntyre points out, the needs of people with disabilities are not considered as needs of a limited group but as the interest of an entire society. Or, more simply, to use the slogan of the World Down Syndrome Day, a fully participatory society is one where “education, opportunities, friends, and love [are] not special needs, just human needs”.

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[1] University of Molise.

[2] Letter from Jean Vanier to Julia Kristeva on 3 november 2009 (my translation from the Italian version).

[3] The difficulty in gathering and evaluating data derives not only from the differences of frameworks used to measure disability, but also from the different level of exhaustiveness of the inquiries conducted in the different countries (WHO and World Bank 2011).

[4] Cf. Barnes and Mercer (2011), Riddel and Watson (2003).

[5] The average pregnancy interruption for fetal malformations (TOPFA) is 5.44‰, with lows in Portugal (0.64‰) and highs in France (10.54‰) and Switzerland (8.06‰). In Europe the number of congenital diseases has constantly grown since 1990; but the number of babies born with those pathologies has remained constant, due to the increased use of prenatal diagnosis and abortion (Euro-Peristat *et al.* 2013).

[6] See the articles on participation in political and public life (art. 29), cultural and leisure life (art. 30), and those relative to the necessary conditions for guaranteeing participation, such as accessibility (art. 9). Moreover, the article on independent living and inclusion in society (art. 19) establishes that countries are committed to adopt adequate and effective measures to "facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community".

[7] Born in the 60s at the University of California – Berkeley, ILM has spread all over the US and many other countries. ILM's fundamental belief is that each human life has value and that people with disabilities have the right to participate in social life by having full control of their lives (Morris 2004). The ILM is operative through the Centers for the Independent Living (CILs). At present there are about 500 CILs in the US, and other hundreds are in Latin America, Europe, Japan (Yang 2013), in South-East Asia, and in Africa. In Europe there are several different approaches to independent living (Townesley *et al.* 2009). The European Network on Independent Living (ENIL), founded in 1989, gathers all the associations whose activity is inspired by the social model. They provide advocacy support and aim to empower people with disabilities. Moreover, ENIL promotes the transferability of the principles of independent living to applicable practices. ENIL's mission can be found at the following link: <http://enil.eu/about-enil/our-mission/>

