

**Participatory & emancipatory approach in disability research.
Possible allies for supporting active citizenship, civil rights and actions of social innovation**

Ivan Traina
ALMA MATER STUDIORUM University of Bologna
Department of Education Studies "G.M. Bertin"

*"We know that equality has never existed and never will, but we do insist that equality of opportunity still
must be sought"*
Franklin D. Roosevelt

Abstract

This paper addresses the debate surrounding the participatory & emancipatory approach in disability research. Its purpose is to answer three research questions related to what extent the participatory approach to research can encourage an active citizenship paradigm for the involvement of disabled people, to what extent emancipation through research can contribute to the affirmation of a civil rights model of disability and to what extent is it possible to consider these approaches as tools that can support the design and implementation of socially innovative actions. The paper is mainly inspired by academic literature and a review of international documents, assuming a disability perspective. It is divided into three main sections. The first explores the participatory approach applied to research as an important component for achieving empowerment and contributing to definition of an active citizenship paradigm to be applied to disability field. The second presents the emancipatory approach to research suggesting possible connections with a civil rights model of disability. The final section tries to assume that the participatory & emancipatory approach to research is a process, rather than an outcome addressed to find a sort of common denominator for the design, prototypisation and implementation of practices of social innovation.

Key words

Participatory & emancipatory research, disability, active citizenship, civil rights, social innovation

1. Introduction

This paper stems from a reflection on the slogan of the disability movement “*Nothing about us without us*” (Charlton, 1998) and its possible application in the field of academic research. The slogan, in line with the United Nation Convention on the Rights of Persons with Disability (UN CRPD henceforward)¹, sheds light on the importance of the involvement of disabled people as with autonomy, desires, choice and control, in all sectors of life. This can be achieved not only by monitoring breaches and legislation, but by achieving social changes, involving the disabled in the research production as active participants (not only as subjects to be researched about) and, as here argued, find conditions to participate in the development and implementation of socially innovative actions.

The debate in this field, started in the 90s with the works of authors such as Mike Oliver, Len Barton, Colin Barnes, Geof Mercer, Gerry Zarb and Stephen Kemmis. Although concepts have been well-developed from a theoretical point of view, they still lack the practical realization of widespread experiences.

This paper intends to focus on the following research issues:

- To what extent the participatory approach to research can encourage an active citizenship paradigm for the involvement of disabled people?
- To what extent emancipation through research can contribute to the affirmation of a civil rights model of disability?
- To what extent is it possible to consider participatory & emancipatory approaches as tools, which can support the design and implementation of socially innovative actions?

It will attempt to find suggestions in literature and international documents on the concept of participatory and emancipatory approach, proposing their possible applications as tools to encourage the active citizenship paradigm, the affirmation of the civil rights model of disability and design of socially innovative actions.

The paper first sets a brief summary of the main positions in relation to the issue of participatory and emancipatory research approaches from a disability perspective, considering these approaches as a means to support the self-determination of disabled people in the research field.

In the last part of the paper, these approaches are proposed as seeds for the growth of projects and prototypes of social innovation. From this point of view, the challenge is to impact on processes and policies for an effective inclusion of disabled people. Not only giving them voice to gather information and feedback, but also fostering their active role, based on principles such as reciprocity, self-determination, accountability and empowerment, for the advancement of the principles included in the UN CRPD.

¹ UN, 2006. Convention on the Rights of persons with Disability, G.A. Res. 61/106, Dec. 13, 2006
Available at: <http://www.un-documents.net/a61r106.htm>

2. Participatory approach to research

In the presentation of the approaches I have adopted Zarb's (1992) theory "*that it is essential to make a distinction between 'participatory' and 'emancipatory' research. The former is a pre-requisite to the latter...*" (Barton, 2005, p. 320). Along the lines suggested by Zarb, I have proposed a brief summary of the essential characteristics relating to the participatory research (PR henceforward) in disability field and its relation with the concept of active citizenship, as described below.

The discourse on PR has its social and historical roots in qualitative research methodologies, starting in the late 1950s and early 1960s, as sort of criticism addressed to the research paradigm used in North America and Europe (mainly based on empiricism and positivism), including rigorous attention to statistical precision.

Three particular attributes are used to distinguish participatory research from conventional research (Krishnaswamy, 2004):

- a) Shared ownership of research projects;
- b) Community-based analysis of social problems;
- c) Orientation toward community action (Tandon, 2005).

Participatory research grew from the practice of adult educators, especially in developing countries Africa, Asia and Latin America that, while working with oppressed people, realized that the rise of specialization and professional expertise had lead to the devaluation of popular knowledge and alternative systems of knowledge production. In particular, thanks to Paulo Freire's influential work on conscientization (Freire, 1972, p. 77), defined as "*the process of developing a critical awareness of one's social reality through reflection and action*", the idea that socially marginalized people could be involved in the production of knowledge, was reinforced. In this view people are active agents in the research process, because when involved in an analysis of their realities they can develop the understanding and the capacity to improve their life.

This concept, if applied to PR, represents an important component for achieving empowerment, because when people participate in determining their own future, they become empowered.

Thus, empowerment can impact on three dimensions:

1. Personal: developing a sense of self-confidence and capacity, undoing the effects of internalised oppression;
2. Relational: developing the ability to participate, negotiate and influence the nature of relationship and decisions;
3. Collective: through actions based on cooperation. (Etmanski & Pant, 2007).

Therefore, considering both conscientization and empowerment as features of PR, it is possible to consider it as an instrument to support socially marginalized people, in particular disabled people, to critically investigate and analyze their reality and then undertake collective actions to bring constructive changes in their lives.

In particular, these changes should consist in the development of critical consciousness of both researcher and participants, improvement of the lives of those involved in the research process and transformation of fundamental societal structures and relationships.

This leads to an impact on the significance of the role that disabled people can play in the research field (development of critical consciousness), on the concept of active citizenship (improvement of their lives) and on civil rights (transformation of fundamental societal structures and relationships), including advancements on ethical issues and providing suggestions for innovative solutions.

The dominant research paradigm indeed tends to ignore ethical issues: information providers are denied any control. It also fails to consider political issues: knowledge is power, and the research process further enhances the power of the elites (Tandon, 2005). This issue has many similarities with what happened with the research on Women, Blacks and the Third World (Stone et al., 1996). Although there are many similarities it should be underlined that what characterizes the latter is present at birth, the condition of disability can be acquired during a lifetime.

According to Sirisena Tilakaratna (1990), PR should try to de-elitise and de-mystify research, making it an intellectual tool which people can use to improve their lives, changing the attitude of being treated only as objects of research.

Moreover, given its commitment to social, economic, and political development in response to the needs of people, proponents of PR have highlighted the politics of conventional elitist research, arguing that orthodox social science, despite its claim to value neutrality, normally serves the ideological function of justifying the position and interests of the wealthy and powerful (Fals Borda & Rahman, 1991; Forester, Pitt, & Welsh, 1993; Freire, 1982; Greenwood & Levin, 2000, 2001; Hall, Gillette, & Tandon, 1982; Horton, Kohl, & Kohl, 1990; McGuire, 1987; Park, Brydon-Miller, Hall & Jackson, 1993).

I will resume the main key features of PR collected from the different authors quoted above, in contrast to elitist research paradigms:

- People can change their role and the dichotomy between subject and object needs to be broken, starting with the use of different terminology, “co-researchers” instead of “research subject”;
 - (Disabled) people themselves collect the data, then process and analyse the information using methods easily understood by them;
 - The knowledge generated is used to promote actions for change or to improve existing local actions;
 - The knowledge belongs to the people and they are the primary beneficiaries of the knowledge created;
 - Research and actions are inseparable – they represent a unity;
 - Research is a praxis rhythm of action-reflection where knowledge creation supports action;
 - Research has to reflect, explore and disseminate the views, feelings and experiences of participants from their own perspectives;
 - There is a built-in mechanism to ensure authenticity of the information that is generated because people themselves use the information for life improvement.

It is important to note here that while the PR approach may at times appear identical to action research, there are two significant ways in which it is different. First, the ideological stance and emphasis on making researchers’ values and premises explicit are generally not reported in the action research approach. Second, action research is at times being undertaken without the participation and control of the participants (Tandon, 2005).

At a theoretical level, referring to this distinction, a further step in the evolution of the epistemology of the PR approach was developed, evolving into a participatory action-research approach and defined as a learning process whose findings are the real and material changes in:

- What people do;
- How people interact with the environment and with others;
- What people mean and what they value;
- How people understand and interpret their life context.

Through participatory action-research, people can understand “what and how” their social and educational practices are, that they are the product of particular circumstances, and how they are reproduced in everyday life (Kemmis & McTaggart, 2007).

The four changes in the process highlighted above also avoid any risk of alienation of the research, in particular because “what people do” can counteract alienation from the product of research, “how people interact with the world and with others” can counteract alienation from the process, “what people mean and what they value” can counteract alienation from the subjects of research and “how people understand and interpret their world” can counteract alienation from interpretations of other.

Although a definition of participatory action-research was provided, what is predominant here is the focus on epistemological and terminological questions related to what is the difference between PR or participatory action-research (Kemmis, 2006), but the contribution of both to the development of research projects based on participation and the involvement of people.

Taking this into account, when trying to define a summative frame of reference, the characteristics of research projects that wish to include disabled people should:

- a) Attempt to promote self-determination and the liberation of creativity for the solution of social problems and the reduction of barriers (cultural, environmental, attitudinal, etc.);
- b) Adopt actions where the focus is on people contributing to solve practical problems in order to generate practical knowledge;
- c) Support participation, empowerment and awareness in the people of their own abilities and resources, in particular in their capability (Sen 1999, 2005);
- d) Involve participants in the entire research process, from the formulation of the problems, the hypothesis to solve, the interpretation of the findings and the planning of collective actions based upon them;
- e) Allow that both the process and results can be of immediate and direct benefit to participants;
- f) Focus on determining needs, increasing awareness of problems and commitment to solutions for the beneficiaries, through a dialectic process and not as a static picture of reality;

- g) Assist participants with data collection and information analysis , using simple methods which enables them to systematise their knowledge;
- h) Encourage the adoption of a view that facilitates processes by which knowledge and solutions can come from participants' conclusions, enabling people to solve their own problems and improve their lives;
- i) Make conflicting action possible, or necessary (Tandon, 2005);
- j) Be addressed to transformation and improvement of the lives of those involved;
- k) Link the local contexts, which the participants know best, to the larger external situation about which the researchers may know more.

2.1 Contributions of the participatory approach to the active citizenship paradigm

On the basis of the characteristics highlighted above and related to participatory approach, I will now consider some of the specific contributions of this approach in order to try to define an active citizenship paradigm to be applied to disability field. The firsts four characteristics (a, b, c, d) are of particular interest here, because they represent what Jenny Morris referred in the debates on the meaning of citizenship for disabled people and the way of viewing citizenship (Morris, 2005).

In fact here I will assume that self-determination (point a), is an important concept meaning that individuals can choose and that full citizenship involves the exercise of autonomy, which in turn refers to *"the ability to determine the conditions of one's life and to pursue one's life projects"* (Lister, 1997, p. 16). Self-determination is therefore used here as key aspect of what it means to be a free and equal citizen.

Considering what is argued by Morris (2005, p. 13) *"a person cannot achieve self-determination if they experience direct or indirect discrimination"* and the fact that unequal access to educational and training opportunities are the two most stark manifestations of discrimination, to allow participation in academic research could represent a way to face these phenomena, providing elements, data and suggestions about how to reduce discrimination and improve access to education, training and research.

With reference to contribution (point b), Morris stressed that:

"Disabled people have emphasised the value of our contribution to economic and social life when we make the case for both anti-discrimination legislation and the resources required for a reasonable quality of life" (Morris, 2005, p. 6).

She also connects with the communitarian emphasis on responsibilities and reciprocity and debates on the limits of social rights. However, if reciprocity justifies placing responsibilities on citizens to make a productive contribution to society, it also demands that those who carry these responsibilities have enough opportunities and rewards to face these responsibilities.

This allows opportunities to research on themes emerging directly from the disabled involved in the research processes from the beginning, with the right support.

Concerning participation (points c and d), this concept is often used when engaging with the debate on social exclusion and the right to be included in mainstream society, removing barriers (cultural, social, economical, attitudinal, environmental, etc.), making disabled people's involvement possible.

This participation gives expression to self-determination and provides opportunities to make contributions. The disabled can participate in the definition of needs, tools (i.e. research and technology), shape cultural attitude, social expectations and political decisions that affect their lives.

In conclusion, self-determination, contribution and participation would guarantee a full and equal citizenship if supported by relevant political and research contributions.

This avoids government policies or programmes operating without being subjected to critical examination, which would produce findings that could be justified only at the convenience of the authority.

In this way, maintaining participation in the definition of the framework of research, in the process of action and in the evaluation of findings, it could be possible to create bodies of evidence capable of addressing challenges, responding to social needs, reducing emerging and existing barriers to inclusion.

According to Reiter and Schalock (2008), active citizenship is "*a shift from dependence and passiveness to autonomy, self-awareness, and self-direction*" (Reiter et al., 2008, p. 5).

Active citizenship should consider the "person" with her/his needs, desires and expectations at the centre of research, actions and interventions. This contributes to support the transition from a common attitude of considering disabled people as victims of a state of passivity, towards a different scenario based on the responsibility and the consciousness of the importance of the involvement in research projects not "on" but "with" disabled people (Reason and Heron, 1986).

All these aspects shall be addressed increasing the opportunities for participation in order to allow disabled people to become co-creators of knowledge and innovative solutions about themselves.

3. Emancipatory approach to research

In this paragraph I will explore the emancipatory approach (ER henceforward) in relation to the civil rights and the oppression disabled people currently experience in their lives. Whilst the participatory research approach fulfils the paradigm of active citizenship, especially regarding concepts such as self-determination, responsibility and participation in the community, ER is more strictly connected with a different understanding of disability, as a problem of lack of rights and, for this reason, here counteracted with the suggestion of a civil rights model.

This understanding finds its roots in the social model, where disability is viewed not as a medical entity or an individual problem, but as a civil rights issue. In this view ER is not only a research approach, but rather part of the possible tool that disabled people can use to improve their rights.

Although participatory research may give support to the social model of disability, it is not inherently associated with it. In ER the research processes and outcomes are part of the liberation of disabled people and of changing society to ensure their full rights.

Here I will also assume what Zarb stated about the difference between participatory and emancipatory research:

“Participatory research which involves disabled people in a meaningful way is perhaps a prerequisite to emancipatory research in the sense that researchers can learn from disabled people and vice versa, and that it paves the way for researchers to make themselves “available” to disabled people - but it is no more than that. Simply increasing participation and involvement will never by itself constitute emancipatory research unless and until it is disabled people themselves who are controlling the research and deciding who should be involved and how” (Zarb, 1992, p 125-126).

Participatory and emancipatory research are therefore two distinct but complementary ways in which researchers can attempt to advance meaningful social change in the lives of disabled people.

In this sense ER is aimed at changing *“the social relations of research, trying to place the control in the hands of researched, not researcher”* (Barnes and Mercer, 1997, p. 17). This means that research projects need to effectively include disabled people not only to gather information and feedback, but also to foster an active role inside the research, gaining more empowerment (Oliver, 1992).

However this is not only a process of empowerment, as in PR where research participants may be given opportunities to tell their stories and analyse their situation, ER is an approach in which disabled people take control of the research processes and products, that are used as tools towards the achievement of their liberation from restrictions brought by social changes.

ER is thus a form of education action in which researchers should be at the service and under the direction of disabled people, no longer only the researched about, but rather co-researchers.

The ER approach in Disability Studies has its genesis in the growth of the Disability movement, the raising awareness of the disillusion of positive and interpretive research paradigms in the 1960s, and the consequent criticism to experts and professionals who professed to speak on the behalf of disabled people, the contribution of organizations as the Union of Physically Impaired Against Segregation (UPIAS) in 1975 and the development of the social model of disability.

Another influential contribution was provided by Mie Oliver's suggestion to follow "*critical inquiry, praxis or emancipatory research*" (in Oliver, 1992, p. 107), most notably for changing social relations of research production, relationship between researcher and researched, and the connections between research and policy (Barnes & Mercer, 1997).

Nowadays the assumption that an ER approach could contribute to make research more efficient, relevant and inclusive for the lives of disabled people, as included in many International documents. The intent of using participatory & emancipatory approaches to disability research responds to the precise indication of the Madrid Declaration² to promote and support the leadership of people with disabilities. The focus on these approaches has been suggested not only in the field of research, but also applied as a possible tool for the development of socially innovative services, products and environments, encouraging accessibility and inclusion.

In order to define what "inclusion" means, I should outline that, broadly speaking, the word refers to the action of promoting and ensuring the participation of people with disabilities in education, training and employment and all aspects of society, providing the necessary support and reasonable accommodation to allow them to fully participate (ILO, 2012). This concept is here used in accordance with the UN CRPD (2006), Art. 2, paragraph 4:

"Reasonable accommodation means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms".

Furthermore the dimension of reciprocity underlying the concept of "reasonable accommodation" emphasizes the importance of the chargeability (responsibility) of human rights, especially the civil and political rights (Articles 1-21 of the Universal Declaration of Human Rights³), including the right to freedom of thought, citizenship, form a family, etc., leading to the construction of the individual as a "capable" subject. Whereby, adopting basic concepts as the co-evolution, the reciprocity and the emancipatory approach expects that the parties involved in a situation can/should both contribute to the success of the action, growing and evolving together.

Reasonable accommodation is required to deal with problematic situations with the adequacy of the available resources. The inclusion is a goal (a regulative ideal) that helps and directs the advance of inclusive processes through gradual steps. For example, "barriers-free" is the regulative ideal, whereas the reduction of barriers - with reasonable accommodation - is the effective and consistent action required to reach the first. From this perspective, inclusion is seen as a broad "ecosystem" that can promote co-evolution of one and all (Canevaro, D'Alonzo, Ianes, Caldin, 2011).

In this sense the emancipatory approach can include the concept of reasonable accommodation and the possibility to be applied in research and other contexts in order to guarantee an effective inclusion.

² Social integration of people with disabilities in the context of the Declaration of Madrid 2002 "*Non-discrimination more positive action equal social integration*" Survey for the initiation of actions to promote non-discrimination of persons with disabilities in education, employment and other spheres of life. 2003 - 2006
Available at: <http://social.un.org/index/Portals/0/ageing/documents/Fulltext-E.pdf>

³ UN Universal Declaration of Human Rights (UDHR), available at: <http://www.unhcr.org/refworld/docid/3ae6b3712c.html>

3.1 Emancipatory approach and civil rights model of disability

In this paper I adopt a model based on civil rights rather than on the notion of human rights, because referring to the latter could be problematic as it includes issues in relation to the universality of rights, conceptualisation and to power effects.

In order to avoid focusing on the definition of humanity, often considered as a *"timeless entity based upon appeals to reasons and absolute truth"* (Mckenzie & Macleod, 2012, p. 15), the concept of civil right is assumed. The concept here adopted derives from the Latin translation of *ius civis* (rights of citizens), and inspired by the 14th Amendment to the U.S. Constitution⁴ as *"the rights belonging to an individual by virtue of citizenship"*.

The adoption of this definition is strictly connected to what is described above as active citizenship paradigm and the role played by participatory approach. In this view civil rights imply a citizen's ability to fully participate in the civil, social and political life of the state without discrimination on grounds of disability, gender, religion, race, nationality, age or sexual orientation, including the insurance of life and safety.

Solely through the adoption of a civil rights dimension disabled people can become active subjects and not passive objects, participants in driving research that should attempt to understand the meaning of events, not only their causes, and to be built upon participation, reciprocity and emancipation. In this way researchers and researched can become agents of change, mutually enriched, providing the elements to present different scenarios and innovative solutions.

Quoting the Hampshire Centre for Integrated Living *"it is only the disabled person who can satisfactorily define his or her needs in terms of the enabling of equal opportunity"* (HCIL, 1990 unpagged) that means to apply the right to inclusion and participation in society on equal terms with others.

In this framework of reference ER could represent an approach, as it was for black people and women movements (Maguire, 1987), and not only a set of technical procedures, but a tool for the demystification of existing ideological, cultural and political structures.

Notwithstanding some differences, alignment with other oppressed groups has allowed disabled people to draw on the experience of feminist and anti-racist theorists in many areas that, like for research, could represent an active role in approaching social needs, innovative solutions and the attempt to reduce barriers (cultural, social, political, environmental, etc.) to equal opportunities and a full participation in democracy and citizenship for all.

If the social model finds the causes of disability in social terms rather than viewing the person's impairment or pathology as the problem, the civil rights model finds innovative solutions in active involvement and emancipation, rather than viewing disabled people only as feedback providers on hypothesis concerning their life designed by non-disabled.

The integrating theme running through this application of active citizenship paradigm finds its transformative aim in approaching disability as civil rights problem, in order to find innovative solutions to respond to different claims such as equity, equality and accessibility (Mckenzie & Macleod, 2012).

The focal point is to position the ER research approach in a civil rights model of disability, here people find the conditions and facilitations to be able to contribute, hopefully not only in the field of research.

⁴ Available at: <http://www.usconstitution.net/constamnotes.html>

This thought is also based on the concept of resilience and the possibility of creating the right environment for active involvement of persons and an effective participation.

From this perspective the role of the researcher is to facilitate these goals, through a participation aimed at contributing to individual, collective and social empowerment and emancipation, as Barnes has argued,

“Emancipatory disability research is not about biology but about commitment and researchers (with or without impairments) putting their knowledge and skills at the disposal of disabled people and their organisations, and the generation and production of accessible and useable knowledge” (Barnes, 1992, p. 115).

This also implies the theme of accountability, a key component of the emancipatory research approach, not only for the researcher but also for the disabled community and its representation. With reference to this issue, it is useful to mention the contributions of Mark Priestley and Lisa Waddington about the new priorities for disability research in Europe, in which it is stressed for the fundamental role of Disabled People Organizations (DPOs) *“as active partners in research rather than the recipients of scientific Knowledge”* (Priestley et al., 2010, p. 240).

This theme, already faced in certain projects such as the British Council of Disabled People’ discrimination project (Barnes, 1991) and the more recent Creating Independent Future project (Barnes et al., 2000), is mostly concerned with the creation of the right environmental conditions to allow inclusion, because there are a lot of challenges in making research inclusive and accountable to disabled people, such as for instance the barriers disabled people face in order to attend meetings or the quality of assistance provided and the way in which research projects run.

The concept of inclusion is part of a broader civil rights model, which supports the view that *“any kind of segregation is ethically wrong”* (Alevriadou & Lang, 2011, p. 2).

This perspective is also emphasized in the principles of the International Classification of Functioning⁵ (ICF) which constructs: the person, the integrative bio-psycho-social model, the consideration of contextual factors, the relational perspective, the quality of processes and systems of education, the participation to social life.

This last one principle is of particular interest as it is strictly related to the concepts of participation, emancipation and inclusion, because, as Stainback and Stainback declared (1990)

“Inclusion is a basic right that no one should earn: governments and communities need to remove barriers and obstacles to social inclusion, with adequate resources and support to create inclusive environments” (Stainback and Stainback, 1990, p. 71).

⁵ WHO, 2001. ICF: *International Classification of Functioning, Disability and Health*. Geneva

3.2 Participatory & emancipatory approaches applied for the design of socially innovative actions

Considering what is exposed in many International and European documents, the idea is to adopt these approaches as tools that can support the shift from a conception of a social/medical model in approaching disability, to one based on active citizenship and civil rights (UNESCO, 1995)⁶, both constituting the framework for the development of social innovative actions for enhancing autonomy, accessibility and inclusion (Oliver & Barnes, 2010 and 2012).

If I wish to re-interpret the suggestion of Zarb about the difference between participatory & emancipatory research, I can consider the former as pre-requisite to the latter. Furthermore, if I compare them, I can state it is possible to see the active citizenship paradigm as a pre-condition for a civil right model of disability.

Citizenship is closely connected to equal rights in society and, according to Kjellberg (2002), three elements are included in citizenship. The first element is civil citizenship, based on the idea that each person is equal before the law, including four aspects: freedom of speech, religious liberty, freedom of thought and right to property. The second element is political citizenship and includes the right to vote and the possibility to be elected. The third element is social citizenship as welfare for all, which means each human being has rights to economic stability, the right to education, employment, social service and health care.

Once I have adopted participatory & emancipatory approaches for sustaining an active citizenship paradigm and a civil right model of disability, I may consider the next step, which could be to provide evidence for the possible practical application of these approaches. This in order to define actions able to respond to social needs highlighted by disabled people and Disabled People Organizations in an innovative way, as tested by the result of Priestley's research, in which concludes that *"the findings show that DPOs in Europe have clear priorities about the kinds of new knowledge and innovation that would be of public benefit"* (Priestley et al, 2010 p. 254).

Taking into consideration Mike Oliver's statement that *"the way to produce unalienated research is to change the social relations of research production"* (Oliver, 1992, p. 101), this section wishes to create links with this suggestion and the principles of Social Innovation (SI henceforward) that is based on the same concept of "change of social relations".

Social Innovations (SI) refers to innovations that are social in both their ends and their means:

"Specifically, we define social innovations as new ideas (products, services and models) that simultaneously meet social needs (more effectively than alternatives) and create new social relationships or collaborations. They are innovations that are not only good for society but also enhance society's capacity to act" (EC, BEPA, 2011, p. 9).

⁶"Persons in special needs must be full participants in the bodies and procedures by which both general laws and policies, as well as disability-specific ones are formulated. This is essential for ensuring the responsiveness, legitimacy and effectiveness of such laws and policies, as well as reflecting the rights of persons in special needs to full participation in the life of the community, including all forms of public decision-making". In Review of the present situation in special needs education. Paris: UNESCO, 1995.

Available at:

http://www.unesco.org/pv_obj_cache/pv_obj_id_C133AD0AF05E62AC54C2DE8EE1C026DABFAF3000/filename/281_79.pdf

In the framework of SI, social and material relationships of research production could change, in particular if this challenge is faced through participation and involvement in the design of socially innovative actions. Along this line, research could gain greater transformative potential (Zarb, 1992) and move towards an effective emancipation.

In order to avoid what Oliver has considered as the failure of feminism and third world research and with the aim of affect practical changes:

“To what can only be called the social relations of research production that the failures of such research can be attributed, and indeed, it is to these very social relations that attention must be focused if research, in whatever area, is to become more useful and relevant in the future than it has been in the past” (Oliver, 1992 p. 112)

What is suggested is to tie the social relations with research production on the basis of what could be innovative for a barrier free society, able to provide answers for a wide range of needs, directly addressed to disabled people primarily through participation. Once good SI practices are developed in tackling social needs, they should be further explored to see if they can be applied to other contexts and countries.

Including the core elements of the SI – namely, novelty, move from ideas to implementation, effectiveness, meeting social needs, effectiveness and enhancing society's capacity to act - in the PR & ER approaches, it is possible to imagine a scenario in which the development and implementation of good practices could meet the civil rights.

Furthermore, the common features of SI can also overlap the characteristics of PR and ER highlighted above, such as: openness and collaboration, a grassroots and bottom-up approach, co-production, mutualism, the creation of new roles and relationships with a better use of assets and resources, supporting the developments of assets and capabilities (Caulier-Grice et al, 2012).

It is in this sense that participatory & emancipatory approaches to research should move locating experiences within a civil rights analysis and social innovation actions, in order to avoid regression into *“mere description or observation, providing only superficial information”* (Stone, 2006 p. 704).

The issues to be faced therefore are not the qualitative nature of the information gathered or the quantity of data collected or which methods are applied, but:

- The theoretical paradigm that guides collection and analysis of data and information (active citizenship paradigm);
- The model of reference to interpret, use and exploitation of results (civil rights model);
- The practical application of findings to the process of developing innovative solution (social innovation actions).

In order to address these issues, what is suggested here is to apply PR & ER approaches for the design of socially innovative actions that could enhance the quality of lives of disabled people. If theoretic research contributions coming from PR & ER approaches were applied to implement ideas or prototypes of social innovation actions, the task could be fulfilled with immediate benefits, such as:

- Local dimension and more effective representation;
- Greater accountability;

- Faster process for the answer to social needs and produce changes;
- Change of relations of research productions;
- Participation in the development of projects (both for research and socially innovative actions) from the earliest stages of design;
- Greater empowerment, emancipation and reflexivity.

Considering the benefits highlighted and matching the relations of research production (where research has a PR & ER approach) with the concept of social innovation, the result could contribute most notably to equalise relationships between researchers (disabled or not) and participants.

This can certainly be done through training, education and research that represent relevant opportunities to improve decision-making skills and self-strengthen of disabled people. In this way the resulting social innovation could go beyond the compensation of the disadvantages through the development of products, services and environments, expanding and ensuring the capacity to choose individually and collectively (Sen, 1999, 2005). These choices do not concern only basic needs such as food, health and education, but also inclusion, accessibility, freedom and rights related to all dimensions of life.

4. Conclusion

The key questions this paper develops have led to the suggestion of a civil rights model, based on an active citizenship paradigm including participatory & emancipatory approaches, aimed at producing more useful and relevant research for people and society, especially if designed and applied to the concept of social innovation.

In order to give impetus to what I have exposed, the participatory & emancipatory approaches to research need to be understood as processes, rather than outcomes, addressed to finding a sort of common denominator for socially innovative practices. Practices designed and developed considering the social relations of research production as process based on investigations realized not “on”, but rather “with” disabled people.

Assuming what Oliver argues about the relation between disabled people and research community, as

“Disabled people have increasingly analysed their segregation, inequality and poverty in terms of discrimination and oppression, research has been seen as part of the problem rather than as part of the solution” (Oliver, 198,7 p.11)

What was here stressed is that research could become part of the solution, avoiding the risk of segregation, offering equality and opportunities, active participation and inclusion, and therefore civil rights.

I suggest adding a new section (inside the dashed box) to Oliver’s scheme (1992), in order to systematize concepts and approaches to a framework of reference already known (see fig.1).

In order to gain more impact and possibly find innovative solutions for concrete changes at political, economic, legislative, attitudinal and behavioural level, it is important to focus on the design of projects characterized by accountability, support for the involvement of disabled people, DPOs, disabled researchers and non. Projects aimed at implementing good practices and prototypes of SI, that intend to find new solutions (products, services, models, markets, processes, environment, etc.) that simultaneously meet a social need, leading to new or improved capabilities and relationships with a better use of assets and resources. In this way, a virtuous circle for implementing the affirmation of civil rights could start.

Finally, I believe a lot of the fundamental principles within the participatory and emancipatory approach are of practical use to those concerned. Research has to assume a different epistemological paradigm of reference, represented by active citizenship. Whereby, adopting the civil rights model to reinforce the same paradigm (that provides the participatory and emancipatory tools), it could be possible for research to develop and implement socially innovative actions. In this way, the social model should try to remove barriers and the civil rights model would consider a world designed and realized without disabling barriers.

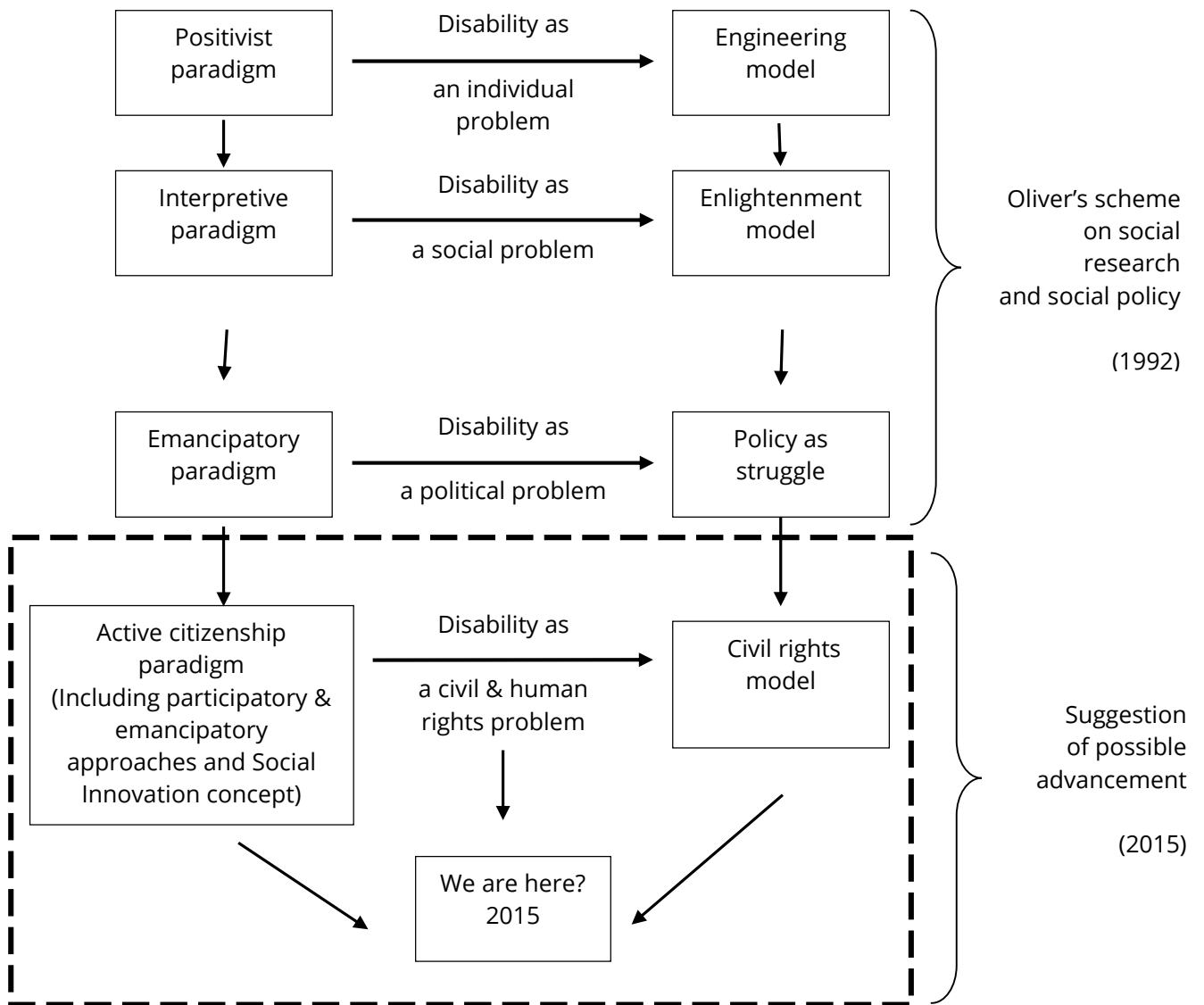


Fig. 1

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List of acronyms

DPOs: Disabled People Organizations

SI: Social Innovation

EC: European Commission

UN: United Nations

ER: Emancipatory Research

UNCRPD: United Nation Convention on the Rights of Persons with Disabilities

EU: European Union

UNESCO: United Nations Educational, Scientific and Cultural Organisation

ICF: International Classification of Functioning

PR: Participatory Research

WHO: World Health Organization